Fundamental rights, democracy and the Human Genome Project: bioethical and biopolitics

Jenífer Naves Soares[1], *Rafael Lazzarotto Simioni*[2]

Abstract

The Human Genome Project constitutes an important contemporary health technology, but it is also a political and economical structure which of production and reproduction of a dominant concept of health. In this perspective, this research aims to discuss the question of the guarantee of autonomy and freedom of choice of the physical-biological patterns of the future generations, in a society in which those patterns are historically reproduced by power relations. For this reason, a methodology of analysis of the Human Genome Project is used in the context of the tension between constitutionalism and democracy, in order to establish an approximation between the contributions of Bioethics, Biolaw and Biopolitics, in the context of a critical perspective of our society. As a result we propose a reflection about the institutionalisation of public hearings articulated from a model of deliberative democracy.

Keywords: Human Genome Project. Bioethics. Biolaw. Biopolitics. Deliberative democracy.

Resumo

Direitos fundamentais, democracia e o Projeto GenomaHumano: bioética e biopolítica

Além de importante tecnologia da atualidade, o Projeto Genoma Humano é estrutura política e econômica de produção e reprodução de conceito dominante de saúde. Nessa perspectiva, esta pesquisa discute a garantia da autonomia e liberdade de escolha dos padrões físico-biológicos das atuais e futuras gerações em sociedade na qual esses padrões são historicamente reproduzidos por relações de poder. Para tanto, analisa-se o Projeto Genoma Humano considerando a tensão entre constitucionalismo e democracia, de modo a aproximar aportes da bioética, do biodireito e da biopolítica a partir de perspectiva crítica da sociedade. Como resultado, propõe-se, para reflexão, a institucionalização de audiências públicas baseadas no modelo de democracia deliberativa.

Palavras-chave: Projeto Genoma Humano. Bioética. Biopolítica. Democracia deliberativa.

Resumen

Derechos fundamentales, democracia y el Proyecto Genoma Humano: bioética y biopolítica

El Proyecto Genoma Humano constituye una importante tecnología de salud de la contemporaneidad, pero también una estructura política y económica de producción y reproducción de un concepto dominante de salud. En esa perspectiva, esta investigación tiene como objetivo discutir la cuestión de la garantía de la autonomía y de la libertad de elección de los patrones físicos y biológicos de las futuras generaciones, en una sociedad en la cual estos patrones son históricamente reproducidos por relaciones de poder. Para ello, se utiliza una metodología de análisis del PGH en el ámbito de la tensión entre constitucionalismo y democracia, de modo tal de establecer una aproximación entre los aportes de la Bioética, el Bioderecho y la Biopolítica, en el contexto de una perspectiva crítica de la sociedad. Como resultado, se propone para la reflexión la institucionalización de audiencias públicas articuladas a partir de un modelo de democracia deliberativa.

Palabras clave: Proyecto Genoma Humano. Bioética. Bioderecho. Biopolítica. Democracia deliberative.

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1. Mestranda jenifernsoares@gmail.com – Universidade do Vale do Sapucaí (Univás) **2. Doutor** simioni2010@gmail.com – Univás, Pouso Alegre/MG, Brasil.

Correspondência
Jenífer Naves Soares – Rua Caxambu, 41, Centro CEP 37410-000. Três Corações/MG, Brasil.

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Considered one of the most significant scientific endeavors of the contemporary world, the Human Genome Project (HGP), in addition to making possible the cure of hitherto incurable diseases, has radically transformed the way we feel, understand and act on the world. The mapping of human DNA and the possibility of intervening in the genetic code through engineering techniques and gene therapy put into question a fundamental question for countries of peripheral modernity such as Brazil: how to guarantee the autonomy and freedom of choice of physical-biological patterns in a society in which these patterns are historically reproduced by power relations?

As pointed out by Michel Foucault[1], standards of health, aesthetic beauty and moral correction are not natural, universal and perpetual, but contingent social constructions, which derive from regimes of power. Faced with these constructions, a social group seeks to impose its standards on others, to the detriment of the diversity of health forms, aesthetic beauty and morality. In this perspective, the HGP also institutionalizes concepts of health, beauty and body efficiency defined by the dominant regime of truth in its time, producing effects not only in the discipline of bodies, but also in the control of populations.

Therefore, the problem with the HGP goes beyond legal issues of protection of privacy and genetic non-discrimination. The mapping of the human genome can redefine patterns of health, aesthetic beauty, moral correctness and bodily efficiency according to the instrumental structures of the capitalist system in which we live.

This means that in addition to bioethics and bio-law, the HGP involves more sophisticated levels of biopolitics oriented to concepts, patterns and values that are dominant in their time and place. In other words, the issue with the HGP is not only whether it is ethical or lawful to use genetic information and practice interventions to prevent future diseases or to improve the health, aesthetics and "performance" of the human being in the world: more than that, the project redefines these concepts themselves.

It is no longer just the symbolic seduction of consumer goods to situate the subject in a particular social group, but rather the inscription of a regime of truth in the DNA of the human being. The HGP not only allows the cure of diseases, but also to redefine the very concept of health, not only by choosing the phenotypic characteristics of our children, but by establishing what should be the "adequate" characteristic based on labor market ideas, beauty standards and identity inscribed in a certain temporality of life in society.

The central question of this research is to understand the ephemerality of the historical pattern of health, beauty and corporal efficiency in a democratic State of law that combines democratic values subject to fluctuations of public opinion with fundamental rights and ideologies that circulate in the mass media. That is, it is about understanding the technological show of the HGP in a context of constant social tension. On the one hand, are the legal principles that protect rights such as privacy, freedom and non-discrimination; on the other, a concept of democracy that seeks to value the will of the majority in the definition of public policies important for the common future.

In addition, the present study brings the bioethical discussion on the HGP to the plan of critical political theory, explaining the material conditions that determine decisions about the future of human nature. To do so, the investigation starts from a description of the project, its historical motivations and purposes, identifying the main risks and challenges that this high health technology presents to society. At another point, a dialogue is established between reflections of bioethics, biopolitics and bio-policy through contributions from the critical theory of society, especially the thinking of Jürgen Habermas[2,3], in order to understand the importance of deliberative democracy in the definition of limits and directions of intervention and genetic control of human beings.

With this in view, we have used here an analytical methodology that explains the relationship between HGP concepts and critical reflections of bioethics and bio-policy. At the end of the article, the relationship between the HGP and the tension between fundamental principles and democracy will be established through the theory of deliberative democracy of Jürgen Habermas[2], which allows us to think of a way of directing the ethical, political and legal control of decisions about the future of human nature in the field of genetic intervention.

The Human Genome Project

The Human Genome Project (HGP) is a scientific landmark for biology, especially for genetics. Its ambitious goals and what it has provided for science to this day characterizes it as one of the greatest scientific endeavors of contemporary times[4]. This is a gigantic project, unprecedented in history, involving hundreds of researchers, research centers and countries around the world. A global project, organized in the form of research networks, that has produced significant impacts in the field of genetics. *The genome is the set of genes that make up each living being. In humans, approximately three billion base pairs of DNA are distributed in 23 pairs of chromosomes, which contain 70,000 to 100,000 genes*[5]. The ability to control, isolate and modify these natural parameters of life puts the HGP in a category of understanding that is not limited to scientific knowledge but which also has significant impacts on the economic, political, legal and ethical knowledge of the world community. There are repercussions of the HGP even in theology, since numerous medical technologies arising from it can affect concepts and values hitherto attributed only to divine designs.

The aim of the HGP was the detailed development of the physical and genetic map of the human genome, i.e. its mapping (place/location of the genes in the DNA) and sequencing (order of bases), respectively. This idea emerged *in scientific discussions beginning in 1984, but it was in 1988 that the US Department of Energy and the National Institutes of Health obtained resources from Congress to begin planning the project*. It began as an international project on October 1, 1990, with a forecast of 15 years and a budget of three billion dollars. Scientists from Germany, China, France, Japan and the United Kingdom participated in the study[6].

Two years ahead of schedule and $400 million below the predefined budget, on April 14, 2003, the full outcome of the HGP was announced. This announcement *represented a powerful instrument for the understanding of biology and human pathologies*[6]. Not only scientists, but also politicians, economists, jurists, philosophers, and theologians expressed an interest in discussing and understanding the new technological and social structures that were being developed in parallel with the scientific discoveries. The initial purpose was to map and sequence 3.1 billion nitrogenous bases in the human genome[7] and thereby *obtain tools for diagnosis and treatment of diseases of genetic cause (gene therapy)*[8]. But the project undressed a vast field of applications from this mapping: genetic testing, pharmacogenomics (personalized medicines), criminal investigation using DNA, infant engineering, gene therapies, racial differences, among others[9]. Numerous scientific investigations of HGP, such as gene identification, enhancement of techniques among others, are also examples of its relevance to science and to the ethical, economic, social, political and juridical issues that it raises to this day.

By its very nature, the HGP is surrounded by many ethical, legal and social uncertainties. Among other issues that the future holds for this new technological experience of society, we highlight the privacy and uses of genetic information, the safety and efficacy of genetic medicine, genetic discrimination and manipulation (eugenics), the use of embryos in research, and pharmacogenetics. All this debate involves respect for equality, human rights and dignity, for self-determination and protection of the individual's privacy, guarantee of the quality of medicine and the idea that information acquired on the human genome is common property and can not be used for commercial purposes.

The knowledge of the genome can lead to interventions in the internal structure of the human being, in its most intimate part, with the possibility of manipulating, selecting and subjecting the body irreversibly to its very being and to future generations. Such knowledge opens the possibility - and the opportunity - to exercise power hitherto attributed to nature, to God in the Judeo-Christian tradition, and to contingency in the post-critical thinking of contemporary philosophy. The problem is that this power, in a capitalist world, will possibly be in the hands of a few economically empowered groups, whose particular decisions may affect the setting of health, bodily beauty and efficiency standards in the present and future.

While Eurocentric and American standards predominate, many will desire children which are blond, blue-eyed, tall, thin and willing to work. And the information from the HGP can provide you with this. But if another country, such as China, for example, becomes a new world power, the standards reproduced in the mass media, the labor market, the school, etc. will be different.

A quick historical review allows us to observe that models of health, beauty and body efficiency change over time. And not only for purely historical reasons, but for reasons of power: the predominant social group imposes its concepts and values, its episteme, its standards of health, beauty and bodily efficiency. Hence, the importance of social movements of resistance, such as the black movement, which fights for the recognition and affirmation of blackness as a right to diversity.

On the other hand, the HGP is responsible for wonderful deeds, such as curing hitherto incurable diseases and gene therapy for parents who are likely to have children with genetic diseases, avoiding the hereditary transmission of conditions responsible for triggering certain diseases. In addition to saving people and promoting a dignified and healthy life, the HGP also works on disease prevention. It is, however, an extremely expensive technology that, because it is restricted to a small economic elite, poses problems for countries that, like Brazil, guarantee by the Constitution the principles of universality of access and integrality of health.

A new frontier for science and bioethics

The HGP revolutionized the field of genetics, constituting the fundamental landmark of a new frontier for science, called the "genomic era" [10,11]. The project involved an international consortium involving about 5,000 scientists and 250 laboratories coordinated by the National Institute of Health (NIH), then presided over by Bernadine Healy and having as scientific director James Watson, Nobel Prize in Medicine with Francis Crick, for the discovery of DNA structure in 1953 [12,13].

Watson was scientific director until 1992, when he resigned due to methodological differences and the patents issue. Francis Collins then took over the role of coordinating the activities of the laboratories and negotiating with the Department of Energy and research centers in other countries, such as Germany, China and Brazil [14]. In 1998, the Human Genome Organization (HUGO), an international coordination body with headquarters in Geneva and offices in Bethesda, London and Osaka was created.

HUGO had the task of boosting international collaboration in the human genomic initiative, coordinating research, attuning the work and organizing the knowledge acquired in a centralized database, the genome data base. To this end, the institution (still active today) had several committees, mapping, bioinformatics, intellectual property and bioethics. However, considering the lack of financial contributions, its work was restricted to simple counseling [7,9,12,14].

Two years after the creation of HUGO, on June 26, 2000, a festive international jubilee announcement was made, with emotional pronouncements from political figures such as Bill Clinton and Tony Blair and leading scientists such as Craig Venter, John Sulston, and Francis Collins. The announcement reported that about 97% of the genome had been sequenced, although the project had not yet come to an end. The newly presented mapping was a result of material analysis of 17 donors [7,8,14].

After three years of the publication of this "draft", on April 14, 2003, scientists announced the complete sequence of the human genome. Brazil, although not officially part of the project, was the second country that contributed the most data to the international gene bank, through the Cancer Genome Project, funded by the Fundação de Amparo à Pesquisa do Estado de São Paulo - Fapesp (Foundation for Research Support of the State of São Paulo, Brazil) [15].

The biological history of human beings is registered in their genome. Unmasking its genetic code makes it possible to diagnose, treat and even cure genetic diseases. In addition, studies show that gene variations do not differentiate human beings from each other, but, on the contrary, show that we all belong to a single humanity 13. It has thus been proved that biological racism and its different forms of social segregation do not have any natural or essential basis, and the separation between supposedly qualified and disqualified populations arise from purely social structures.

Future risks and challenges

As with other technologies, the health advances promoted by the HGP are ambiguous: while improving the quality of life it can exterminate genetic characteristics judged as superfluous or undesirable at a certain historical moment. In other words, while allowing the cure and prevention of genetic diseases, the HGP also creates the possibility of eugenic intervention in the characteristics of humanity.

These new technologies can bring benefits to mankind, but there are unpredictable risks. Faced with such possibility it is imperative that scientists and society be careful not to exceed the ethical limits imposed by respect for the integrity and dignity of human life. Science must be used to make people's lives more and more dignified [4], safeguarding human and fundamental rights.

This is one of the challenges of the HGP: defining how the knowledge acquired will be used from now on [13]. It is worth remembering that the ethical, legal and political implications were and still are so important that in 1990 the Ethical, Legal and Social Implications Research Program -ELSI- was created as part of the project [6]. In the United States, for example, the NIH and the Department of Energy each allocated 3 to 5 percent of the annual budget to the ELSI. It was the first time in the history of science and technology that a considerable part of the funding of a major scientific project was reserved for the study of its social and ethical impacts while the work was still being done [12].

Many perspectives, both positive and negative, arise with the HGP: genetic intervention (genetic manipulation and gene therapy), embryo selection, genetic discrimination, eugenics and cloning, among others [4,13]. However, as Chut points out, *much more important than the domain of the technique used is the knowledge about how it is being used, or rather, the purposes that are being used, so that it can be valued in the ethical and legal point of view* [16]. Corrêa also points out that *the HGP therefore seems to promote this new scientific ethos in which the production of knowledge and biotechnology would be inseparable from a permanent ethical vigilance* [17].

However, there is an even more complex problem behind these ethical appeals. Because of its profitable potential, the human genome also involves economic issues of the highest relevance. Historically, incalculable profit opportunities have always placed ethical and legal demands aside and, today, above all, money and power seem to be the two social structures that command the destiny of mankind [18]. We may be interested in ethical, moral and legal issues, and we may even respect, by conviction, the freedom and the way of being of others. But when money and power enter into the equation, the result is always subject to interference. This is because these two elements constitute social structures of systemic integration, whose rationality works at the level of instrumental and strategic reason, predominant in contemporary society [19].

In this type of rationality, the ends justify the means. The market presents the cure of diseases as an end, and then the means necessary to arrive at this result "arise", even if they involve risky research with human beings, eugenics, creation of databases with genetic information, discrimination of humanity between people who may or may not pay for access to these therapies etc. The market can also present productive efficiency as an end, legitimating all means necessary to achieve this goal, including the use of genetic information to design the most appropriate psychological and physiological profiles for this or that function in a corporation or social organization.

Genetic discrimination and bioethics

It is not just about the price of life insurance, which can now be calculated taking into account the genetics of each individual. The HGP enables social discrimination based on genetic criteria - a "genetic discrimination" alongside the already known forms of discrimination: racial, gender, of belief and way of life. In the genome field, this kind of segregation becomes more serious and subtle because it is hidden in technical-scientific discourses supposedly endowed with objectivity, rationality, impartiality and truth. By referring to nature, genetic discrimination is based on biological discourses, not ideological criteria, although both are socially constructed.

The legal issues of protection of privacy make it difficult to solve some problems generated by genetic mapping. States can adopt inclusion policies for historically excluded groups, but how can we create policies to include mortal gene carriers in social security or, to cite another example, how to include in health plans people who carry terminal disease genes?

Mediation work can point the problem to a scenario where such an inclusive policy would be plausibly and convincingly implemented. But this would presuppose the appropriation and disposal of genetic data, with the recipient of the public policy of inclusion giving up their privacy in order to prove their situation. The problem would then shift to the issue of secrecy and control of genetic information.

In this context, the leakage or misuse of genetic information could generate perverse consequences, such as the lifetime unemployment of the affected person or their isolation from certain social groups. The question, then, would be how to control the use of genetic information, forbidding it for certain purposes but not for others? How to guarantee, for example, the discount on the contribution to social assistance for someone who, because of their genes, has a shorter life expectancy? Furthermore, how can we ensure that this information is not accessible to the health plan, life insurance or the employer who intends to invest in the training and qualification of this individual genetically "programmed" to die, in statistical terms, before returning the investment?

This is how the instrumental reason of economics thinks. In this way, bioethical reflection can often be trampled, suffocated and colonized by this rationality. The HGP is not only a new and wonderful health technology, but also a new economic and political structure. It is knowledge that can enrich those who own it and access to it may be restricted.

Deliberative democracy and the future of human nature

To keep the HGP from turning into a project of *liberal eugenics* [20], genuine democratic spaces of participation, discussion and deliberation about what each community wants for the future are essential. Fundamental rights are important social achievements to ensure the privacy, health and well-being of the citizen, and must be preserved in all societies. But technology linked to the HGP goes beyond health. It is also an economic, political, scientific and technological structure that operates in a very sensitive area of society: the imaginary construction of possibilities to improve life, cure diseases, improve the genetics of the offspring, and plan and control phenotypic characteristics of children, etc.

This imaginary network of possibilities is so strongly justified by liberal political thought that any attempt to impose curbs or conditions on its realization is seen as conservative, obscurantist, retrograde, or at least excessively cautious, inconveniently prudent behavior. In the context of discourses constantly reproduced by our society's mass media, it would be an act of cruelty to deprive people with economic conditions of having access to practices that improve their life, such as the treatment of diseases and the planning of the biological life of their offspring.

However, this posture is incompatible with the senses produced by the HGP. The concepts of disease, improvement, or planning of biological life are not a question of liberal economics, but an issue inscribed in the very structure of capitalist society in which we live. After all, who has the legitimacy to say what should and should not be considered a better life? Who can define the "normal" body pattern, from which everything else is abnormal, deficient, or deviant? Who has the right to establish what we should expect from the genetics of our children?

Historically, the emperor, the monarch, the king and the state have been the references of discursive authority that, by diverse political strategies, have been credited the legitimacy of defining these standards [21,22]. Besides them, during the twentieth century, doctors, anthropologists and other professionals of science also defined the "normal" and the "pathological", establishing criteria at the time considered scientific in spite of being purely ideological.

Today, however, the issue is more complex: transnational organizations also produce highly selective discursive systems for ways of life that are supposed to be seen as models for the future. Companies that reward a particular professional profile over others produce and reproduce standards of "exemplary collaborator", confirmed by the subtlety of the unequal distribution of salaries and positions. Not to mention the publicity that, along with mass entertainment programs, is an imaginary institution of reality [23], with standards and normalizing concepts of what we must wish to fill the eternal emptiness of our lives and what we must abandon as heavy baggage to get to happiness.

The State no longer holds the exclusive and hegemonic power of authorized speech about what is health, well-being, aesthetic beauty and performance at work. Organizations also exercise this power. Even organized social movements can inscribe "styles" of behavior in their militants and sympathizers, which extrapolate, with seductive rebellion, state and corporate domestication.

For these reasons, neither the state nor the organizations should be left to the discursive definition of the standards desirable for the future of humanity. Only the deliberative and direct participation of all those affected can legitimize such decisions. Whether through public hearings, or through the expansion of democratic spaces of popular participation in the political decisions of the government, the legislature and the judiciary, liberal eugenics can only be avoided through critical and honest discussions.

Legitimacy is not to be confused with mere legality or conformation with the law, neither is guaranteed only with bioethical foundation or argument subordinated to the political morality of the community. It is the popular participation that gives legitimacy through discursive inclusion and the guarantee of access to knowledge, issues and alternatives under discussion. In order to do this, the only force allowed in the formation of consensus must be the best arguments, not that of economic power, organized political or religious militancy, or the power of specialized knowledge of scientists and health professionals.

In deliberative democracy, as proposed by Habermas, [24] no one has privileged access to the truth, correction or sincerity. The technical discourse of the specialist is one among many others, without any hierarchical relation between them. Under ideal conditions of debate, legitimacy lies in free and autonomous consensus among the participants, not in the imposition of hegemonic opinion by the force of scientific authority, money or power.

The solution of the equation between constitutionalism and democracy, which composes the challenge of constructing the democratic state of law, can be precisely in the institutionalization of discursive procedures appropriate to deliberative democracy, with direct, free and autonomous participation of all those affected by the decisions. In this perspective, HGP health technologies, together with the political, economic and scientific structure they articulate, can find, in public hearings, the space for critical discussion to produce rational, legitimate decisions that are coherent with what we really want for the future.

Deliberative democracy requires that the state, organizations, and mass media do not decide alone what health, aesthetic beauty, and job performance should be considered for current and future generations. According to this model, only people impacted by the consequences of a decision have the legitimacy to take it. Therefore, it is the affected, not the "owners" of the HGP technology, who must decide on its use. In this context, the role of the State is reconfigured, which now guarantees spaces and procedures for democratic deliberation.

Only consensus on what should be considered "genetic improvement" can authorize practices related to the human genome. But if among those affected by these procedures are descendants who were not born, how to guarantee the freedom of future generations about genetic decisions made by parents in another historical context? One might assume that the use of genetic intervention technologies to prevent disease would be justifiable in the future as well. However, the very concept of disease is part of a network of historical discursiveness sustained by relations of power.

As Habermas observes, *would the first person, who determines another according to his own preferences in his natural essence, also not destroy those equal freedoms existing between equals by birth, in order to guarantee difference?*[25] Do we have the right to choose, for our children, the kitsch reproduction of successful liberals?

Of course, there are several challenges to establishing deliberative democracy in countries of peripheral modernity such as Brazil[26]. Public hearings and other instruments of popular participation are ways that point both to new challenges and to the solution of old problems of representative democracy models of the modern State.

Final considerations

Ambivalent like all technology, the HGP raises both the prospect of curing diseases and improving the conditions of human life and the perverse possibility of eugenic liberal selection. But, unlike the technologies that work in the sphere of prostheses and consumer goods outside human life, innovations made possible by the HGP allow to inscribe a system of discursiveness about the DNA of the human being.

Especially in countries of peripheral modernity such as Brazil, the guarantee of autonomy and freedom of choice of physical-biological standards is a relevant problem for bioethics and bio-law. This is because these patterns, constructed and reproduced in the discourses of society, are historically structured by relations of power. Therefore, it is not only a matter of guaranteeing the freedom, privacy and intimacy of genetic information, but of participating in the very definition of the concepts of dignified life, health, aesthetic beauty and performance in the work that we want for the future.

The institutionalization of public hearings, based on a model of deliberative democracy such as that of Jürgen Habermas, is one of the possible ways for a new form of democratic legitimacy on such crucial issues raised by HGP technologies. Therefore, such a model requires that all those affected by a decision know, discuss and deliberate on issues that concern them.

Far from being a representative model, in which individuals are elected and work articulating and negotiating alliances and strategic political positions, deliberative democracy is able to guarantee inclusion, equality, right of speech and not coercion for all participants in the deliberation. The ideal conditions for discussion in this form of democracy provide for the free and autonomous formation of conviction, according to which the only coercion allowed is the force of the best argument.

There are several Brazilian experiences of public hearings that point the way to this new form of democratic construction of legitimacy. The debates about priorities in public policies and legal issues involving traditional communities, as well as committees of ethics in research whose composition is not limited to specialists, demonstrate the legitimacy that spaces of direct popular participation can have in the difficult and sensitive to social structures decision-making of the contemporary world. Such spaces are not messianic solutions that can solve all the problems arising from the possibilities opened by the HGP, but Levitical solutions, that is, small daily solutions, which, in the whole, accomplish the best we can do.

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