

# Genome Editing The New Eugenics?

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**ABSTRACT:** The human genome editing techniques, which surpasses preimplantation genetic diagnoses at this time, has posed a number of ethical, philosophical, social and legal issues over the years that are far from resolution or any consensus. The challenge, nowadays, is the option between the refusal to use them or, by the contrary, making them available, in particular, to the prospective parents of ART, who are a wide range of *consumers* of these techniques. The possibility of DNA editing, and the immense solutions of CRISPR technology reprogramming the heritable genome brings us the debate of a modern form of eugenics. For parents and the programmatic choices they make, with DNA editing to their will and repudiating the genetic inheritance of their children, with impact on their personal integrity and identity, bringing human dignity, and human nature itself, to the epicentre of the debate and a new form of *generational* responsibility and, in a social context, a form of *genetic aristocracy*. The latest Nuffield Council on Bioethics report, "Genome Editing and Human Reproduction: Social and Ethical Issues," published in July 2018, further inflamed the debate. Seeming to accept, albeit cautiously, that the issue may be ethically acceptable in some circumstances, namely the guaranty of the welfare of the person and that it does not result in any disadvantage, discrimination or social cleavage. The timeliness and importance of the subject require us to focus our analysis considering the ethical and legal issues raised by the topic.

**KEYWORDS:** CRISPR technology, Genome Editing, Eugenics; Bioethics, ART, Human Dignity

## Introduction

On April 14, 2003, the International Consortium of the Human Genome Project (HGP) announced the decoding of 99.99% of genome – “the book of life” was finally opened and bioengineering, as had enormous evolution.

On September 20, 2017 was published an article by British scientists from the Human Embryo and Stem Cell Laboratory at The Francis Crick Institute – who had been authorised to research on human embryos – about the genome editing, having concluded that, in addition to the purely scientific issue" (...) *CRISPR–Cas9 mediated genome editing is a powerful method for investigating gene function in the context of human development*" (Fogarty et al. 2017).

They would not come to that conclusion by *simply* studying mouse embryos, heating up the debate on the need of using human biological material.

The development of CRISPR, Clustered Regulatory-Interspaced Short Palindromic Repeats, (in 2012, which makes genetic modification faster, cheaper and easier, compared with previous techniques) is an important tool in genome editing (in genome editing refers to the CRISPR/Cas system used to edit DNA at specific locations in the genome), being a technology constantly evolving. In April 2018 was published an information stating that an improved version had been published, allowing the simultaneous editing of multiple genes (Sadhu, Bloom, Day, Siegel, & Kosuri 2018) and, already in August 2018, Chinese scientists announced, successfully and with a new approach – compared with the 2016 method of CRISPR-Cas9 – the genome editing in human cells achieved genetic correction in heterozygous human embryos (Zeng et al. 2018).

Although scientific advances make this debate urgent and even if slower than the speed of science it is, undeniable, imperative. Bioengineering is placing human as, not only the creator – being seduced by discovery and daring to be in control of something which before was in the hands of destiny or faith (or God, if you wish), at the time called *the threshold of biological modernity* (Foucault, 1988, first published 1976) – but also its subject, in which the human being is still being defined by (*bio*) *policies* strategies.

Many are the implications of CRISPR, being undeniable and legit our desire to *heal* our children of eventual illnesses they may have, or even to programme them to achieve certain characteristics or skills. The truth is these ethical issues about the human being, his qualities and human essence, about

the acceptance of imperfection and tolerance of the difference, and about the society, in which one way or the other we are going to become (Fukuyama 2002; Sandel 2007), are still to be answered and paths to be unfold.

It is admittedly tempting the possibility of the scientist to be able to act on the genes level, in an exercise of human being programming. As recognised by the President's Commission for the Study of Ethical Problems in Medicine, Biomedical and Behavioral Research, that in 1982 (p. 10) stated that “*genes are perhaps the most tangible correlates of who a person is as an individual and as a member of a family, race, and species.*”

Genes are, in fact, a true legacy for future generations and the *heritage of humanity* as stated in art. 1.º of Universal Declaration on the Human Genome and Human Rights of UNESCO symbolically referring to the human genome.

This *playing God* has its consequences, and these new techniques reveal, in the words of the French philosopher Michel Foucault (1988, first published 1976), (new) forms of power, o *bio power*.

### 1. Good in Birth: The Eugenic Debate

*Eugenes* is in the epicentre of the debate mainly because of its historical connection. Many historical events, of poor memories, such as the atrocities of the World War II, and the well-known experiments in human beings in Nazi concentration camps with the intention of defining the Aryan race, justified this intention by promoting the *purification of the specie* removing the impure that ended in the genocide of nearly 10 million human beings.

Above all, by the remarkable advances in genetic engineering, we are undeniably entering a new era of eugenics, aiming the cure and/or improve features, either to enhance the existing genetic code, or to introduce new genetic material to change human multigene characteristics.

On one hand, the diagnosis of *in vitro* diseases is a form of genetic investigation and the separation of unaffected embryos to transfer to the womb (Oliva Teles, 2011, 988). The early identification of hereditary diseases, such as Tay-Sachs and cystic fibrosis, that is proved lethal, are the most expressive advantages of technology. (Thinking about all the issues that this matter raises and its permeability, one should simply consider the questions related to wrongful life e wrongful birth, regarding the medical liability for breach of *legis artis* in the identification of pathology that may have caused, in case of being identified, the end of a pregnancy, which results in the birth of disabled child, and consequently the right of the parents to be compensated, even questioning if the child has the right to be also compensated for his life (Almeida Araújo 2016)).

Social tolerance to these techniques is increasing, as well as the range of options and diseases that is able to identify. We are beyond that. In addition, it is exactly from here, especially on the appeal to the possibility of creating (more) perfect human beings (humanly acceptable despite the natural imperfections of the human being) in the field of genetic engineering.

If PGD gives parents the possibility to avoid certain diseases, the path to select embryos with the *right genes*, human cloning, as well *baby design*, the technology acting on the manipulation of germ-line and the inherent heritage genetics, is open.

Does genetic engineering bring us the question of eugenics? For us the answer is yes. It is not the one with historic connotation, brought by the Nazi experiments, as stated by Coutts & MacCarrick (1995, 164),

“(...) beginning with the 1933 Law for the Prevention of Congenitally III Progeny, 350,000 schizophrenic and other mentally ill persons were involuntarily sterilized, and marriage or sexual contact between Jews and other Germans was banned. Several hundred black children and 30,000 German Gypsies were sterilized. By 1945, when the allies liberated those remaining in Nazi concentration camps, six million Jews, 750,000 Gypsies, and 70,000 German psychiatric patients had been killed by the Nazis. As a result of the German experience, eugenic thought dropped to its nadir, and to the present day, the term "eugenics" invokes a sense of horror in some people.”

If it is (will) not be a *Nazi eugenics*, the truth is that we are faced with a new *eugenics*, with difficult consequences to draw and where the boundaries between treatment and improvement, positive and negative eugenics, good and bad, or simply better, with several shades of grey are to be considered.

Right from 1982, with Recommendation 934 of Parliamentary Assembly of the Council of Europe, is referred that is within the right to life and human dignity, the right to inherit the genetic patrimony that has not been artificially changed.

The paradigm of consent presents itself with a new point of view. Considering these new paradigms, we can take it a bit further as the *procreative altruism* (Douglas & Devolder 2013), where, along with individual interests, other altruistic considerations should manifest at the time of selection for the others' well-being.

Or, in another Conception, the *procreative beneficence*, where,

*“couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information”* (Savulescu 2001, 414).

Nevertheless, and regardless of autonomy and consent, another question arises and should be considered: the tolerance for difference, inclusion and solidarity, accepting unconditionally the difference in an empathic and civilized society (MacKellar & Bechtel 2014, 193). Infirmity may become a problem, since it could be resolved at first, can have serious repercussions as it seen.

An even more extreme situation when dealing with the matter of *enhancement* where, without pathology at first, the issue related to technology consumption is debated, that *offer* us children as we selfishly wish and desire, even with ground, the best features we can endow.

The scientific opportunity and the right to choose can be a truly form of justice (Buchanan, Brock, Daniels, & Wilker 2000), considering the consequences of those with disabilities who do not have the opportunities, that, at least in abstract, arise.

If so, it should be considered that, in this field, the local asymmetries will be immeasurable. Not to mention, of course, the developed and underdeveloped countries, where is a huge cleavage to the access to those technologies depend not only on the local investment, but also on the social and health policies that are promoted. Establishing a work to promote the distribution of local and global genetic therapy, as referred by Hildebrandt and Marron (2018) in their article about Justice in CRISPR/Cas9.

The *pressure*, humanly justifiable, of having a child without any illness that ultimately is discussed on a moral obligation level, the truth is, we have, on the other hand, a political and economic environment arising.

We should not disregard the investment in technology – where the *bio value* represents a strong component of economic interests – as well as charges and cost-effective of *producing* citizens without disabilities. That can lead to *well-being* policies with the scope of removing offspring pathologies, but also to guarantee social sustainability policies by comparing the healthy with the sick, in a *eugenics budget* idea.

We do not neglect that, in addition to the local investment that each country decides or can do about this matter, the State effort that led to the creation of the Human Genome Project Consortium and, therefore, the recognised interest that this matter raises on different levels, and may lead to media *pressure* with consequences in terms of public opinion, much needed on the legitimation process.

Since the technological progress has a connection not only in the private sphere, with participants but in society itself (Habermas 2015 (First Published 1968)), not being a dimension of *mere* personal attitude or *simple* reproductive freedom but also in the political dimension on the understanding of society, whose permeability to speech and clarification promote the biopolitics and legitimate it.

In the words of Habermas (2015, first Published 1968, 121)“ *the translation process between science and politics ultimately refers to the public opinion.*”

## 2. Genetic Responsibility (And Liability)

These biotechnological processes raise a certain commodification of human beings, particularly in the *creation* of men according to another's motivation, leading to a certain human being, with

characteristics chosen *à la carte* and, therefore, influencing future generations, which implies a huge responsibility.

If science gives us options, especially on a PGD level, the theory of a new responsibility is emphasised: the genetics responsibility, in a (new way of) generational solidarity exercise.

Removing destiny (or God, if you wish) from the genetic inheritance, we take the responsibility of the genetic programming our children into our own hands. Causing the loss of chance, or a new non-dear opportunity that we may have given cause.

The well-born will (would) be the result of improvement of the human species, no longer born of genetic randomness, but instead of an *enhancement* process where is possible to change each inherited patrimony avoiding genetic disorders, on one side, and on the other skilfully creating a new and improved human being when compared to his genetic luck.

This *duty* to act, or not, especially on the tracking and prevention of hereditary diseases can be argued, as stated by Daar (2017, 191), in theorising the *duty* of ensuring our children, on the current scientific knowledge, the maximum health and/or preventing future illnesses

The bioethicist Harris (2009) comes to a true *moral obligation* of the enhancement of genetic inheritance that biotechnology allows. As stated by Savulescu (2001, 425), in his *procreative beneficence*, assumes the choice of non-disease genes with an impact on well-being is morally required. Assuming that our choice must be guided with the scope to reduce disabilities, giving the parents the opportunity to select whatever presents with better perspectives of well-being (Savulescu & Kahane 2009, 290).

This view leads to other and new questions. On the downside, will be the (moral) censorship and the parents' responsibility to choose, if not considered right. (Sparrow 2007).

There is no easy path. Taking the genetic destiny into our hands, the responsibility of doing or not doing, or the extent to which you do, becomes ours and we shall render account to our children, individually, and the society we leave them.

The emergence of values that will result from this debate will be the way to follow on the crossroad we are facing today and the subsequent obligation to legislate accordingly. Not excluding that, at the moment, changing ways is as fast as the knowledge-based society allows and economic interests may dictate, especially creating an eventual false belief of necessity regarding the access to these technologies thereby encouraging their acceptability (The *power* of marketing should not be desconsidered in the creation of consumer needs convictions).

Yet, from the decision on keeping the genetic randomness or choosing programmatically, the eventual consequences of excluding opportunities and skills from that decision may arise the eventual responsibility of parents on the loss or genetic alteration (Christiansen 2017).

As the reproductive autonomy and the right to genetic heritage are in conflict, the truth is we have a question of delimitation of that autonomy, since with these new techniques and respective medical intervention, *reprogenetics* (Green 2007), gains ground and with different limits from nature and human reproduction (Kimbrell 1997) making an even less tight border between the conflicting interests and practical conformation of both.

It is understood that genetic engineering and the promised *well-being*, puts on us, as individuals and while members of a society, the consequences of *bad genes* and its existence, as well as choices, or the lack of them, that we do (or may do) on behalf of our children and (bio)society that we built upon those choices, also making a biological citizenship (Rose & Novas 2003).

From this genetic engineering, which is being provided today, our children will demand responsibility from their genetic programmers As referred by Habermas (2008, first Published 2003, 13-14) the producer should be responsible for their consequences, possibly unwanted, that exist according to the organic choice made for your life and life history.

Beyond that, we are at the absolute threshold of human creation, irreversible and unrepeatable, and constitutes an appropriation of identity, especially genetic, and the historicity within, of others. As Habermas (2008, first Published 2003, 14) states, the appropriation of historicity of each makes it handle irreversibly “*for this poor soul there are only two alternatives, fatalism and resentment.*”

### 3. Human Dignity And Genetic Aristocracy

The human being as the first and last reference of the State is the primary element of the society. (In the Portuguese Constitution, the principle of human dignity appeared for the first time with the revision of 1951 Constitution of 1933).

Human dignity won the projection that we find today with the end of the World War II, particularly in International texts such as the Universal Declaration of Human Rights, adopted in 1948 by the United Nations, and is now clear and concise, referring Nietzsche, Sloterdijk (2000, 41) postulates, at the time of conflict between those “*who create the human being to be small and those who create him to be great, amongst humanists and super-humanists, human beings’ friends and friends of superman.*”

We are in this historical moment where technology acts on human beings. We are in this debate regarding the human nature itself.

Far from being perfect, the human species, especially the next generation, has a strong attraction to provide it – in addition to avoid hereditary diseases – with improved characteristics, in the possibility of having *posthumans* as called by Buchanan (2011). If so, we are on the threshold of altering the human nature itself and human dignity becoming measurable, and create qualitative differentiation. In Silver’s vision (2007, first Published 1997) of making our children the *GenRich* distinguishing them from *Naturals*.

Genetic engineering and intervention on the human genome level, and its endless options, brings the human being to the epicentre of the debate, since it is about this, or the human embryo, which acts on and raises a new dispute about the status of human embryo (Canotilho & Moreira 2007, 449), with greater acuity in scientific research.

In this theme, and amongst different situations, we can identify problems of genetic modification, on a germ-line (in addition, the human cloning) level, and the alteration of inherited genetic heritage, raises a problem about the exploitation of human beings, on a Kantian view, in which becomes not an end in himself but an object on the hands of others (Beyleveld & Brownsword 2001). According to his selfish will, and thus predetermining the manipulated without being able to do anything or have the free choice to do it. The discussion between what is a patient and a consumer is opened, which for us lies in the distinction between a human being and a thing. A border that is required by the human dignity, establishing man as an end and not just a mere object.

Genetic engineering had the gift to blur the line of distinction. Suffice to think in all situations of genetic mutation on a *non-patient* (i.e. without a pathology), for example in terms of characteristics such as beauty or intelligence. At this point it is undeniable that already exists a series of social mobility regarding this theme of *choosing* aesthetics features or physical or intellectual skills, not to mention the options of gender. Raising Singer (2009, reprinted 2013, 277), in his article Parental Choice and Human Improvement, first draws attention to advertisements in American newspapers of the most prestigious universities offering large sums for students to donate sperm or eggs, conferring to prospective parents, who reach for any ART technique using the donation of gametes or embryos, the possibility of having a child with the donor’s characteristics. I.e. given the attendance in a prestigious university, most likely the students are to be intelligent and physically gifted and thus transmitting these characteristics to their offspring, enhancing the possibility of *having a child with pedigree*.

Although it establishes, with a degree of certainty, this distinction if we are willing to become consumers (Nuffield Council report de 2018–vd. infra point 4—where for the heritable genome editing does not refer specifically to patients) of this biotechnology, which is admittedly alluring.

Whatever the option, the time is of (re)positioning the human being. This existential hype is for Kaufmann (2015, 40) the third source of philosophy, placing it at the time of *distress*, the philosophy of existence when human being is confronted with extreme situations, when his own existence is questioned, as referred by this same author quoting Ernest Bloch (2015 40), *distress* encourages thinking. Therefore, this is a moment of *distress*, the shift from human nature to *post-human* nature (Buchanan 2011).

Regarding the ethic matter of admissibility of altering the genetic heritage, artificially, with the scope of improving an individual, changing his historical background, and thus his identity to a limit of behaviour and *moral enhancement* is the boundary between the threshold of humans and things.

#### 4. Some Ethical Analysis

In 2016, The Danish Council on Ethics, in its report (2016) on the technology advancement CRISPR recommended that safety interventions should be ensured regarding genetic modification for the elimination of possible diseases in gamete or zygote.

None the less, some board members (Danish Council on Ethics, 2016, 11) identify, with great relevance, not only the risks to be considered but also other questions, especially ethics. The first argument lies in the lack of therapeutic urgency, important side effects, during not only the investigation period, but also those who may manifest later, after birth (what alone would involve research on human species to be able to identify them) and which being an intervention in the genome may appear in the following generations. The subject of human nature is given great prominence, since the intervention, especially in the unborn, without their consent alters its genome and subsequent generations. In addition to these arguments, the options, both in terms of gamete donation, as well as the perception of normality and tolerance are raised with great acuity.

In a different perspective, other board members (Danish Council on Ethics 2016, 13) weight the risks/benefits of genetic manipulation solely to eliminate serious illnesses (admitting that are still grey areas that should be considered) under penalty of the controlling effect that the manipulated may feel as well as a certain standardisation of characteristics.

On the year, the Nuffield Council on Bioethics (2016), regarding the use in human reproduction, especially in genetic alteration of embryos, showed concern in the study of ethical issues, recognising the controversy, what would be necessary to demonstrate the safety and effectiveness of techniques, being necessary a debate before these possibilities turn into an effective choice, as its public debate, affects the technology development, allowing the distinguishing between what is acceptable and unacceptable, reducing ambiguous areas.

Already in 2018, the Nuffield Council on Bioethics (2018) report, "Genome Editing and Human Reproduction: Social and Ethical Issues," inflamed the debate setting out a series of principles that leads us to a way of legitimise, not considering neither unethical nor morally unacceptable, the procedures for the heritable genome editing, in some cases, with the assumption principle of "welfare of the future person" (Nuffield Council on Bioethics 2018, 75). In addition, and cumulatively, to evaluate other conflicting interests and interests of others, society and humanity. In any case, the report sets out a series of principles to consider, recommending an extended public debate on this matter. In any moment, the report is limited to therapeutic uses. It is therefore crossed the risk that until now was red light.

#### Conclusions

Genetic engineering, especially the mutation of characteristics, is at risk of assuming as a form of *deliberate quality control* (Habermas 2008, first Published 2003, 30) creating life according to the preferences and wishes of third parties towards the object of creation, which will live with them through the *composition of the their genome*.

The power of today in tomorrow's generation in the determinism of their life projects, collides with the freedom of children and their self-determination, with no way to reverse the process, creating an instrumental link between both, figuratively in a conception between creator and creature and, in this case, to fulfil expectations, waiting, sooner or later, to project and constitute a characteristic or quality that will manifest.

In genome editing there is an effective *enhancement* of people's characteristics, imposing a change in spontaneity of self-perception, therefore any eventual limitation of the autonomy of life, actions and consequences, may place, either by determinism, or by sharing actions put into practice by the manipulator given the fact that they may be conditioned by selected genetic characteristics. Contrary to what happens in the negative eugenics, there is no reason to suppose that there is consent in artificial mutation which leads to a unrepeatable way of life with no way of turning back.

If so, on one hand we have the possibility to improve each person's characteristics to better adapt the organism to environmental conditions, ensuring a better and improved quality of life, enhancing the opportunities that may reasonably aspire.

The boundary is dubious and the choices are not easy, considering the endless options that science present us, the distinction between a patient and a consumer is not easy but, for us, is the essential distinction between reproductive autonomy and the right to genetic inheritance, between *creating* a human being and *creating* a thing.

In any case, and no matter the option we make, the responsibility we take from destiny (or God, as you may wish) becomes ours.

## Acknowledgments

This work is financed by national funds by FCT - Foundation for Science and Technology, under the Project UID/DIR/04053/2016. To Lusíada University – North (Porto) and CEJEA – Centro de Estudos Jurídicos, Económicos e Ambientais, to whom we are grateful.

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