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REPRODUCTIVE GENOME EDITING

AND SOME OF ITS CHALLENGES

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Introduction

Whereas until a few decades ago the possibility of altering the human genetic code appeared to be a science-fiction prospect, in recent years the remarkable scientific progress in this field made it a tangible option. On the one hand, such a revolutionary technology holds the potential to alleviate the suffering given by severe diseases, but on the other hand it certainly involves quite a few risks and uncertainties; for this reason, reproductive gene editing represents one of the most discussed topics among contemporary bioethical debates. The debate surrounding this topic is extensive and calls into question different disciplines, raising not only ethical, but also legal and scientific issues; this thesis represents an effort to analyse, from an ethical perspective, at least some of the intricate questions arising from the opportunities that gene editing offers.

It could be argued that the actual potential of gene editing technologies fully manifested its magnitude in 2018, when the researcher Jiankui He declared the birth of two babies who had undergone a gene editing intervention performed by him and his team; in the first chapter, this specific case will be examined, along with an overview of gene editing and its different kinds of interventions – including the fundamental distinction between somatic and germline procedures – and a brief comparison of other genetic engineering technologies already established.

As will be seen, the peculiarity of reproductive gene editing is that it entails that its modifications will be inherited by future offspring and, therefore, by future generations, rather than affecting only the individuals who actually underwent the intervention; the second chapter will, in fact, focus on some of the main arguments advanced against gene editing in this regard, such as safety issues, the consent and autonomy of future generations and the supposed integrity of the human genome.

While the second chapter concerns pragmatic and categorial factors of the ethics of gene editing, the following one focuses on sociopolitical considerations, based on the standpoint of a scholar that could be described as ‘bio-conservative’: Inmaculada de Melo-Martín. Even though she does not circumscribe her arguments to gene editing, but examines more broadly ‘reprogenetic’ technologies,

she labels genetic engineering as wrongful, based on equity and justice-related concerns. Such observations will be critically examined partly in this chapter and partly in the fourth and last one, which focuses on the topic of gene editing in relation to the disability rights critique. In order to adequately frame the issue, the analysis will begin with an outline of the main models of disability, among which the one endorsed by Tom Shakespeare of 'critical realism'. His position is particularly significant because it illustrates – from the perspective of a person who, prior to being a scholar, is an individual that experiences disability – that the concrete suffering of bodies cannot be entirely addressed through changes in the social sphere. It will be then discussed the 'slippery slope' objection, frequently brought up in relation to these practices.

Chapter 1 - Reproductive Genome Editing

1.1 He Jiankui and the World's First Genetically Modified Babies

> Two beautiful little Chinese girls, named Lulu and Nana, came crying into this world as healthy as any other babies a few weeks ago. […] Grace [the mother] started her pregnancy by regular IVF, with one difference: right after we sent her husband's sperm into her eggs, we also sent in a little bit of protein and instructions for a gene surgery. When Lulu and Nana were just a single cell, this surgery removed the doorway through which HIV enters to infect people.
>
> A few days later, before returning Lulu and Nana to Grace's womb, we checked how the gene surgery went by whole genome sequencing. The result indicated that the surgery worked safely, as intended […]. After birth, we again deep sequenced Lulu and Nana's whole genomes. This verified the gene surgery worked safely: no gene was changed except the one to prevent HIV infection.
>
> The girls are safe and healthy as any other babies.[1]

On 25 November 2018, these words from a YouTube video shocked the world and marked a turning point for the scientific community: Jian-Kui He, a Chinese researcher of the Southern University of Science and Technology, in Shenzhen, announced that he and his team had brought into the world the world's first genetically modified babies, Lulu and Nana.[2]

Two days later, at the Second International Summit on Human Genome Editing in Hong Kong, He further investigated his experiment: his team had recruited eight volunteer couples – but only seven remained until the end – in which all the male participants were HIV-positive and all the females were HIV-negative. As He explained in the video, the sperm of the men was "washed off", to get rid of HIV, and then injected into the women's eggs along with CRISPR/Cas9 protein.[3]

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[1] The He Lab (2018), *About Lulu and Nana: Twin Girls Born Healthy After Gene Surgery As Single-Cell Embryos* [Video], Youtube, https://www.youtube.com/watch?v=th0vnOmFltc&t=21s.

[2] He was also involved in the birth of a third gene-edited baby in 2019, but there is a lack of confirmed information about the outcome of this experiment.

[3] Li J., Walker S., Nie J., *et al.*, *Experiments that led to the first gene-edited babies: the ethical failings and the urgent need for better governance*, "Journal of Zhejiang University-SCIENCE B (Biomedicine & Biotechnology)", 20:1 (2019), p. 33.

CRISPR stands for "Clustered Regularly Interspaced Short Palindromic Repeat" and it's a genome-editing technique, often associated – as in this case – with the Cas9 protein; applying this procedure, He and his team disabled in Lulu and Nana's embryos a gene called CCR5 in order to prevent HIV from entering the cell, thereby making them immune to the HIV virus.[4]

As a matter of fact, the experiment's outcome itself was unclear: CRISPR operated differently on each of the twins, because in one twin it modified only one of the two CCR5 copies, whereas in the other one it edited both. Also, in both twins, some of cells had modified CCR5 genes, but other cells did not, making Lulu and Nana what are known as 'mosaics': individuals with cells that carry modifications in their DNA.[5]

Nonetheless, it is crucial to highlight that He operated at the germline level, so these modifications could be passed on to the twins' offspring:[6] this might entail the transmission of undesirable changes to future generations.[7]

The spread of the news triggered conflicting opinions: while the experiment was perceived as a breakthrough in the field of gene-editing, at the same time as more details about the trial emerged, the legitimacy of it came increasingly under scrutiny, not only in China but also internationally. This atmosphere resulted in a statement endorsed by 122 Chinese scientists on the night of November 26, via which He's initiative was officially condemned as unethical because of its potentially serious off-target risks, not to mention ethical considerations. This was followed by similar statements from various institutions, such as The Scientific Ethics Committee of the Academic Divisions of the Chinese Academy of Sciences, and also by some correspondence in *The Lancet* by the Chinese Academy of Medical sciences:[8]

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[4] Li, Walker & Nie, *op. cit.*, p. 33.
[5] Greely H.T., *CRISPR'd babies: human germline genome editing in the 'He Jiankui affair'*, "Journal of Law and the Biosciences", 6:1 (2019), p. 117.
[6] Alonso M., Savulescu J., *He Jiankui's gene- editing experiment and the non- identity problem*, "Bioethics", 35 (2021), p. 564.
[7] Li, Walker & Nie, *op. cit.*, p. 34.
[8] *Ibid.*

> We are opposed to any clinical operation of human embryo genome editing for reproductive purposes […]. In the rapidly developing area of genome editing technology, our scientific community should uphold the highest standards of bioethics in undertaking responsible biomedical research and applications and uphold our scientific reputation, the basic dignity of human life, and the collective integrity of our scientific community.[9]

In fact, though CRISPR/Cas9 can be considered the most convenient gene-editing technique in comparison to the others currently available, this doesn't necessarily imply its efficiency: it's been observed in a study that human embryo editing shows an efficiency rate of 15% for single gene correction.[10]

However, ineffectiveness is not the only problem with CRISPR-Cas9: there might be off-target alterations which would cause defects, disabilities and other diseases[11] and the 'mosaicism' induced by gene editing may reduce any therapeutic effects.[12] In particular, the modification of CCR5 plays a role in resistance against the West Nile Virus infection, a reemerging pathogen that can cause fatal encephalitis;[13] more generally, it is difficult to pinpoint all the possible side effects, thus making it almost impossible to foresee and to deal with their related consequences.

1.2 Artificial Reproductive Technologies: Is GGE Necessary?

The case of Lulu and Nana stands as a powerful example of the dangers of gene-editing technologies when applied without proper regulation, but it also highlights the possibilities that this field may offer. It is helpful, at this point, to consider the broader context of this kind of innovation: we can define genome-editing as a range

[9] Wang C., Zhai X.M., Zhang X.Q., *et al.*, *Gene-edited babies: Chinese academy of medical sciences' response and action*, "Lancet", 393 (2018), pp. 25-26.
[10] Liang P.P, Xu Y.W., Zhang X.Y., *et al.*, *Crispr/Cas9-mediated gene editing in human tripronuclear zygotes*, "Protein Cell", 6:5 (2015), p. 366.
[11] Li, Walker & Nie, *op. cit.*, p. 34.
[12] Baumann M., *CRISPR/Cas9 genome editing – new and old ethical issues arising from a revolutionary technology*, "Nanoethics", 10 (2016), p. 144.
[13] Glass W.G., McDermott D.H., Lim J.K, *et al.*, *CCR5 deficiency increases risk of symptomatic West Nile virus infection*, "The Journal of Experimental Medicine", 203:1 (2006), pp. 35-40.

of techniques that allow for the modification of the genetic code contained in the DNA to correct genetic mutations, to substitute or to remove genes.[14]

We can trace back the idea of replacing a non-functioning part of DNA with a healthy one to Theodore Friedmann and Richard Roblin,[15] whose theses stood on the scientific advancements made the 1970s regarding the study of DNA and on the discovery of 'restriction endonucleases': enzymes capable of cutting DNA at specific sites.[16] The discovery of recombinant DNA by Paul Berg played an important role as well and it involves four relatively simple steps, based on relatively simple criteria: a gene is identified, it is cut and isolated from the DNA molecule, it is joined to a vector and it finally is transferred inside a receiving cell.[17] It is mainly thanks to this research that the developments in genetic engineering methods have resulted in the possibility of gene therapy.[18]

It's then necessary to make an important distinction: the genetic interventions can be performed on somatic cells, hence those of an adult organism, or on the cells present in gametes and in an early zygote; on this basis, we can differentiate between somatic and germline interventions. As mentioned earlier, the efficacy of the second kind of intervention is not limited to the individual receiving it, because its effects can be passed on to descendants, hence impacting future generations on the long term.[19] Reproductive genome editing (rGE), thus, includes a specific category of genetic modifications carried out on gametes, their progenitor cells and embryos.[20]

Germline Genome Editing (GGE) represents one of the possible ways of exerting control over the human reproduction, but it's not the only one. As of now, there are several Artificial Reproductive Technologies (ARTs) available, and additional

[14] Magni S.F., *Bioetica*, Carocci Editore, Roma 2011, p. 68.
[15] Battisti D., *Procreative responsibility and assisted reproductive technologies*, Routledge, New York 2025, p. 19.
[16] *Ibid*.
[17] *Ibid*.
[18] *Ivi*., p. 20.
[19] Magni S.F. *Bioetica*, cit., p. 69.
[20] Palacios-Gonzáles C., *Reproductive genome editing interventions are therapeutic, sometimes*, "Bioethics", 35:6 (2021), p. 557.

ones will probably be accessible in the future.[21] Let us consider, for example, the In Vitro Fertilization (IVF) with embryo transfer: an oocyte is artificially fertilized and then transferred into the uterus;[22] regardless of the potential physical and psychological complications related to this procedure, it is becoming more widely adopted[23] because it frequently serves as the solution for couples or individuals facing infertility problems.

IVF can be complemented with Preimplantation Genetic Diagnosis (PGD), a procedure that enables the identification of certain genetic traits in early embryos acquired *in vitro* before the uterine transfer; this technique is mainly applied to select embryos that are free from genetic mutations that may cause the development of a hereditary disease in the child.[24] In fact, the conjunction of IVF and PGD has been demonstrated to be effective in preventing the transmission of over 250 genetic diseases, such as cystic fibrosis and Huntington's disease,[25] and as of now PGD procedures have an error rate of 1-3%, thus PGD constitutes an option with a high degree of reliability.[26]

Such a procedure, however, is not free from ethical concerns, first of all because it entails that the information gathered is used to select the healthy embryo to be transferred, thereby discarding the remaining ones.[27] Nonetheless, PGD can enable the selection of the future child's sex: it is no coincidence that the first PGD application, which dates back to 1989, was a sex selection for medical reasons. Yet there is nothing to prevent such a selection from being performed for non-medical reasons, to the point that this kind of procedure is legal in the United States, where the percentage of clinics that provide it has increased from 42% in 2006 to 72.2% in 2017, mainly due to the hight demand within the country.[28] At the same time,

[21] Battisti D., *Procreative responsibility and assisted reproductive technologies*, cit., p. 6.
[22] Battisti D., *Procreative responsibility and assisted reproductive technologies*, cit., p. 7.
[23] *Ivi,* p. 8.
[24] *Ivi,* p. 9.
[25] Gyngell C., Douglas T., Savulescu J., *The Ethics of Germline Gene Editing*, "Journal of Applied Philosophy", 34:4 (2017), p. 499.
[26] Battisti D., *Procreative responsibility and assisted reproductive technologies*, cit., p. 10.
[27] Magni S.F., *Bioetica*, cit., p. 65.
[28] Battisti D., *Procreative responsibility and assisted reproductive technologies*, cit., pp. 10-11.

sex selection for non-medical reasons has raised significant legal and ethical concerns, and remains illegal in many countries, including Italy and Germany.[29]

The main objection to PGD, then, in addition to the disposal of the unselected embryos, is that in the future it could be used to obtain information not only about genetic diseases, but also about traits like intelligence and appearance;[30] this could lead to the possibility of guiding reproductive choices, which is often considered associated with eugenics,[31] as will be further discussed later.

While reproductive genome editing eliminates the issue of discarding surplus embryos, the theme of embryo selection is more complex and it cannot be claimed that the simple adoption of rGE in place of PGD effectively resolves the issue. The reliability of PGD has already been highlighted and, although not without its problems, it currently represents a relatively secure and established procedure. For this reason, since PGD already proved to be effective in the prevention of many genetic disorders, opponents of GGE argue that the use of germline modification is unnecessary for most cases.[32]

Four main concerns about GGE have emerged as the most relevant: violation of human dignity, disrespect of the autonomy and the physical integrity of the future child, discrimination against people with disabilities and of the fear of immoral usage of technology, such as the ultimate example of eugenics.[33]

It is worth to acknowledge, however, that genome editing also offers certain advantages over preimplantation genetic diagnosis; for example, when both parents are homozygous for an autosomal recessive disorder all embryos will inherit two copies of the pathogenic allele: as a result, there are no disease-free embryos available for selection, so GGE can be the only procedure that enables

[29] Battisti D., *Procreative responsibility and assisted reproductive technologies*, cit., p. 11.
[30] *Ivi*, p. 12.
[31] Magni S.F., *Bioetica*, cit., p. 66.
[32] V. Hammerstein A.L., Eggel M., Biller-Andorno N., *Is selecting better than modifying? An investigation of arguments against germline gene editing as compared to preimplantation genetic diagnosis*, "BMC Med Ethics", 20:83 (2019), p. 2.
[33] *Ibid.*

the prevention of transmission of single gene disorders, such as cystic fibrosis.[34] Moreover, most common diseases – including diabetes, coronary artery disease and common cancers – are the result of a polygenic disposition combined with environmental factors, and PGD and IVF have a limited capability to select against polygenic diseases, while GGE allows multiple modifications to be made within a single embryo, making possible simultaneous targeting of different genes.[35]

It is also worth adding that approximately 19% of women undergoing IVF only produce one viable embryo[36] and that older women, or women who have had cancer treatments, may experience difficulties in obtaining a high number of egg cells;[37] consequently, the number of embryos available for selection may be very limited. In the future, a complementary use of GGE with PGD could raise the number of embryos available, thus increasing the chance of achieving pregnancy.[38] Furthermore, the use of GGE to eliminate diseases from the embryos' DNA may also imply, on a larger scale, a reduction in the occurrence of these diseases within the gene pool, thereby lowering their incidence in the future generations.[39] So even in cases where IVF and PGD can be employed to prevent genetic diseases in the immediate offspring, GGE may offer the added advantage of ensuring that these conditions are not passed on subsequent generations as well.[40]

Do these cases offer a valid basis to justify the research and development of GGE? It is often emphasized that circumstances under which PGD is ineffective are extremely rare, implying that GGE may still be rejected, but even if the number of such cases is extremely low it can be difficult to argue that this fact alone makes GGE illegitimate, therefore withholding some couples the opportunity to have

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[34] Ranish R., *Germline genome editing versus preimplantation genetic diagnosis: Is there a case in favour of germline interventions?*, "Bioethics", 34 (2020), p. 63.
[35] Gyngell C., Douglas T., Savulescu J., *The Ethics of Germline Gene Editing*, "Journal of Applied Philosophy", 34:4 (2017), p. 501.
[36] *Ivi*, p. 500.
[37] Ranish R., *Germline genome editing versus preimplantation genetic diagnosis: Is there a case in favour of germline interventions?*, "Bioethics", 34 (2020), p. 64.
[38] *Ibid.*
[39] Gyngell C., Douglas T., Savulescu J., *The Ethics of Germline Gene Editing*, "Journal of Applied Philosophy", 34:4 (2017), p. 501.
[40] *Ivi*, p. 500.

healthy children; hence, the 'rarity argument' doesn't offer a constitute a convincing moral thesis to ban GGE.[41]

According to the 2017 report on 'Human genome editing: Science, ethics, and governance' issued by the U.S. National Academies of Sciences, Engineering and Medicine (NASEM), clinical research and application using GGE should be allowed, and in some scenarios

> Heritable genome editing would provide the only or the most acceptable option for parents who desire to have genetically related children while minimizing the risk of serious disease or disability in a prospective child.[42]

This conclusion represents a significant turning point toward the growing acceptance of germline genome editing,[43] but it doesn't imply a total endorsement of GGE: any clinical trial or future application is considered allowed only under specific criteria, first and foremost is the "absence of reasonable alternatives" and the availability of data on the risks and health benefits of the intervention, and this procedure would be limited to the prevention of "a serious disease or condition".[44]

In conclusion, GGE may offer potentially greater benefits than PGD, especially in certain cases such as those previously discussed, but it also raises numerous additional concerns – ethical as well as safety-related – that will be taken into account in the following chapters.

1.3 Identity-Affecting Procedures

The debate surrounding genome editing rises several dilemmas, including whether it should be considered an identity-affecting procedure and thus whether it brings with it the non-identity problem.[45]

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[41] Ranish R., *Germline genome editing versus preimplantation genetic diagnosis: Is there a case in favour of germline interventions?*, "Bioethics", 34 (2020), p. 64.
[42] National Academies of Sciences, Engineering, and Medicine, *Human Genome Editing: Science, Ethics, and Governance*, The National Academies Press, Washington DC 2017, p. 133.
[43] Ranish R., *Germline genome editing versus preimplantation genetic diagnosis: Is there a case in favour of germline interventions?*, "Bioethics", 34 (2020), p. 61.
[44] National Academies of Sciences, Engineering, and Medicine, *Human Genome Editing: Science, Ethics, and Governance*, The National Academies Press, Washington DC 2017, p. 7.
[45] Magni S.F., *Is Germline Genome Editing Identity-Affecting?*, "Humana.Mente Journal of Philosophical Studies", 46 (2024), p. 1.

The non-identity problem is implied by what Parfit defines as the 'time-dependence claim': the idea that a person's identity is closely tied to the specific moment of their conception, meaning that even a slight alteration in that timing would result in the existence of a different individual.[46]

Traditional normative views entail that an action can be considered right or wrong if it has an impact on a person, and as such are defined as 'person-affecting views', and they leave the non-identity problem unresolved:[47] an individual's poor health condition caused by genetic modifications can't be considered a harm to that person, since – according to the earlier mentioned time-dependence claim – they would have not existed at all without the intervention, so there is no individual who can be said to have been harmed by this action, thereby making GGE morally permissible.[48]

With different normative theories, namely the 'impersonal views', the non-identity problem no longer holds, because these prospectives argue that an action may be right or wrong depending on whether it makes the world a better or worse place,[49] so according to this view GGE may be morally wrong if it results in a bad health condition for an individual, because it would have caused impersonal harm by making the world a worse place.[50] As Parfit presents these two outlooks about the principle stating that "We should do what is in the best interest of those concerned",[51] he highlights the fact that

> When we can only affect actual people, those who do or will exist, the difference between these forms of the principle makes, in practice, no difference. But when we can affect *who* exist, it can make a great difference.[52]

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[46] Magni S.F., *L'etica tra genetica e neuroscienze. Libero arbitrio, responsabilità, generazione*, Carocci Editore, Roma 2019, p. 128.
[47] Magni S.F., *Is Germline Genome Editing Identity-Affecting?*, "Humana.Mente Journal of Philosophical Studies", 46 (2024), p. 2.
[48] *Ivi*, pp. 6-7.
[49] *Ivi*, p. 2.
[50] *Ivi*, p. 7.
[51] Parfit D., *Rights, Interests and Possible People* in H. Kuhse, P. Singer (eds.) *Bioethics. An Anthology*, Wiley-Blackwell, Oxford 1976, p. 371.
[52] *Ibid.*

Hence, if we conclude that GGE is not an identity-affecting action, the difference between person-affecting and impersonal views becomes irrelevant and any negative effect caused by gene editing can be considered harmful, causing it to be morally wrong on both accounts.[53]

The 'identity objection' claims that the modification of an embryo through genome editing results in a numerically different person than the one who would have come to existence without that procedure.[54] As Battisti argues, it is crucial to highlight the distinction between pre- and post-conceptions rGE procedures, because to create an embryo specifically for the purpose of modifying using rGE it's a choice with different moral conditions than the modification of a pre-existing embryo prior to its implantation in the mother's womb: our moral obligations depend on the context within our control, and in the pre-conception scenario any parents' decision will directly determine which future child will be born, while in the post-conception case parents deal with the same numerical identity of their future child.[55]

Battisti refers to Parfit's "origin view", according to which

> each person has this distinctive necessary property: that of having grown from the particular pair of cells from which this person in fact grew.[56]

Hence, the decision to modify (or not) through genome editing the embryo from which a future person will develop can be described as a "same person choice", according to Parfit's terminology,[57] thus these are decisions that do not affect either the number, or the identity of future people:[58] in the post-conception context, the embryo's numerical identity is the same of the future individual, so the application

[53] Magni S.F., *Is Germline Genome Editing Identity-Affecting?*, "Humana.Mente Journal of Philosophical Studies", 46 (2024), p. 7.
[54] Battisti D., *Procreative responsibility and assisted reproductive technologies*, cit., p. 153.
[55] *Ivi*, pp. 164-165.
[56] Parfit D., *Reasons and Persons*, Clarendon Press, Oxford 1984, p. 352.
[57] Battisti D., *Affecting future individuals: Why and when germline genome editing entails a greater moral obligation towards progeny*, "Bioethics", 35 (2021), p. 491.
[58] Parfit D., *Reasons and Persons*, cit., p. 356.

of GGE doesn't bring a new numerical identity, as it would in the pre-conception context, it just affects the qualitative characteristics of the same child.[59]

Applying this distinction to the He Jiankui case, which has been introduced in the first paragraph of this chapter, as Magni notes we can consider He's initial choice to gene-edit the two babies as identity-affecting, though only in an indirect way, since it starts the events that lead to the selection of those embryos. However, his very act of modifying them presupposes their prior existence; hence, Lulu and Nana's intervention cannot be considered an identity-affecting action, since it was applied on embryos, not on gametes.[60]

In fact, He could have acted differently and chosen not to modify the embryos, since there is a temporal gap between this decision, the selection of the embryos through IVF and the actual act of editing and this gap leaves room for alternative choices, which could still have been made even later on: even after the editing procedure, he still could have chosen not to implant them in the mother's womb and, as a result, they would have never been born.[61]Thus it is the actions preceding and following the GGE procedure, rather than the intervention itself, that can be considered identity-affecting.

On the other hand, in cases where the time gap between gametes' selection and their editing is non-existent, or instances where the modifications occur prior to the selection, there were not alternatives for the person who is conceived, that would have not existed otherwise.[62]

Since it has already been pointed out that, in cases where we cannot affect the identity of those who will exist, the distinction between personal and impersonal views does not arise, if we consider genome editing as a non-identity-affecting procedure – at least in instances where it follows the embryo selection – we can evaluate it only from a person-affecting perspective. Therefore, there may be good

[59] Battisti D., *Affecting future individuals: Why and when germline genome editing entails a greater moral obligation towards progeny*, "Bioethics", 35 (2021), p. 494.
[60] Magni S.F., *Is Germline Genome Editing Identity-Affecting?*, "Humana.Mente Journal of Philosophical Studies", 46 (2024), pp. 9-10.
[61] *Ivi*, p. 8.
[62] *Ivi*, p. 11.

reasons to perform such a intervention when it is safe and beneficial, and reasons not to do so when it brings a risk of danger.[63]

[63] Magni S.F., *Is Germline Genome Editing Identity-Affecting?*, "Humana.Mente Journal of Philosophical Studies", 46 (2024), p. 12.

Chapter 2 - Objections to GGE

2.1 Safety and Security

When analysing the ethics of genome editing, three different types of factors can be considered: (I) *pragmatic* aspects, that mainly depend on the current state of science and that are, therefore, in a way tentative, such as the safety argument or the risk-benefit analysis. (II) *Sociopolitical* aspects, pertaining to the social impact of technologies, for example their capacity to exacerbate or mitigate inequalities. (III) *Categorical* aspects, which are often closely related to deontic reasons and highlight categorial limits according to which certain actions may be performed.[1]
A comparison between past and present bioethical discussion on genetic engineering reveals a significant shift in ethical deliberation: whereas in the past the debate revolved mainly around categorical or sociopolitical perspectives, once genome editing became a tangible possibility the focus was redirected, leading to an ethical analysis of intervention techniques - especially in relation to their efficiency and safety.[2]
As mentioned in the previous chapter, various concerns are usually discussed in the contemporary debate regarding genome editing, but the issue of safety seems to constitute the main topic. As a matter of fact, from the beginning of the debate in question this aspect was identified as a major limitation, that needed to be addressed before gene editing could be applied to humans:[3] current empirical evidence indicated that any clinical application remains highly unsafe at present, but as research rapidly progresses they might soon become sufficiently safe.[4]
The scientist and genome-editing proponent George Church captures the perplexity felt even among experts in the field, when contemplating the possibility

[1] Almeida M., Ranisch R., *Beyond safety: mapping the ethical debate on heritable genome editing interventions*, "Humanities & Social Sciences Communications" 9:139 (2022), p. 7.
[2] *Ibid.*
[3] Rath J., *Safety and Security Risks of CRISPR/Cas9* in D. Schroeder, J. Cook, et al. (eds.) *Ethics Dumping. Case studies from North-South Research Collaborations*, Springer, Cham 2018, p. 109.
[4] Rubeis G., Steger F., *Risks and benefits of human germline genome editing: An ethical analysis*, "Asian bioethics review" 10:2 (2018), p. 136.

of using CRISPR/Cas9 on humans:[5] "What is the scenario that we're actually worried about? That it won't work well enough? Or that it will work too well?".[6]
In fact, gene editing interventions pose various risks to the people involved: as already mentioned in the previous chapter, the most evident potential repercussions are the so called 'off-target' mutations, in other words unintended changes to the genome that might lead to the onset of cancer and other diseases.[7] Furthermore, errors in the editing process can result in severe outcomes such as DNA deletions, gene mutations and the removal of entire chromosomes, bearing also in mind that, in the case of germline level interventions, such modifications would be transmitted to future generations;[8] consequently, the modified genes could propagate within the human gene pool, resulting in entirely indefinable outcomes.[9]
Another potential negative consequence could be mosaicism, that is the occurrence of some modified and some unmodified cells in the embryo, and may cause cognitive and developmental impairments;[10] moreover, the fact that some body cells remain unedited could restrict therapeutic effect.[11] In general, the outcomes in this context are still very unpredictable[12] and in order to prevent further side effects it is necessary an extremely precise level of editing, to prevent the modification of non-intended sequences, and so far these standards remain unmet.[13]
An additional issue is the distinction between treatment and enhancement procedures, given that even the possibility itself of applying this distinction is often debated: how should we draw the line between the two different purposes, and is

[5] Baumann M., *CRISPR/Cas9 genome editing – new and old ethical issues arising from a revolutionary technology*, "Nanoethics" 10 (2016), p. 140.
[6] Vogel G., *Embryo engineering alarm*, "Science", 347 (2015), p. 1.
[7] Gyngell C., Douglas T., Savulescu J., *The Ethics of Germline Gene Editing*, "Journal of Applied Philosophy", 34:4 (2017), p. 504.
[8] Wiley L., Cheek M., LaFar E., et al., *The Ethics of Human Embryo Editing via CRISPR-Cas9 Technology: A systematic Review of Ethical Arguments, Reasons, and Concerns*, "HEC Forum" 37:2 (2025), p. 275.
[9] Rubeis G., Steger F., *op. cit.* p. 136.
[10] Wiley L., Cheek M., LaFar E., et al., *op. cit.*, p. 275.
[11] Baumann M., *op. cit.*, p. 144.
[12] Wiley L., Cheek M., LaFar E., et al., *op. cit.*, p. 275.
[13] Baumann M., *op. cit.*, p. 144.

it morally relevant to do it? In a systematic review – regarding the main arguments for and against the use of CRISPR/Cas9 – has been shown that in literature the uses of this technology aimed at preventing diseases, especially 'serious' ones, were generally perceived and defined as therapeutic or similar to standard medical treatments, while interventions intended to improve someone's capacities or make them 'better than normal' were classified as enhancements.[14]

On this point as well, in his case study about CRISPR/Cas9 Johannes Rath focuses his analysis on two distinct terms and two thematic areas: he discusses '*safety*' in relation to "the protection of humans, animals, plants and the environment from unintentional harm", whereas '*security*' pertains to intentional harm and it may involve, for instance, the military field.[15] Rath emphasizes that this second aspect, in contrast to the first, has become a relevant issue only in recent times, after government representatives recognized it as a threat to national security: genetic human enhancement, in particular, raises major security concerns.[16]

Indeed, in some countries allowing the use of gene editing for these kinds of purposes – such as increasing IQ or physical endurance – may have various pervasive security consequences in both military and economic fronts, at national and international levels.[17] In fact, genome editing interventions may evolve in very different scientific, ethical and legal directions: given their dual-use potential, they can 'cut both ways'[18] as it has been recognized even by an official institution such as the World Health Organization (WHO) Expert Advisory Committee, which in 2021 published a report aiming for the establishment of criteria for the governance of human genome editing and in its contents there is a specific mention of "potential dual-use applications":[19]

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[14] Wiley L., Cheek M., LaFar E., et al., *op. cit.*, p. 275.
[15] Rath J., *op. cit.*, p. 108.
[16] *Ivi*, p. 109.
[17] *Ibid.*
[18] Badea A.R., Feeny O., *Genome Editing Dilemma: Navigating Dual-Use Potential and Charting the Path Forward*, "Bioethical Inquiry" 22 (2025), p. 101.
[19] WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing, *Human genome editing: a framework for governance*, World Health Organization, Geneva 2021, p. 7

> For example, human genome editing to give resistance to chemical pollutants or to radiation for space travel could also have military applications with respect to resistance to chemical or nuclear weapons.[20]

It cannot be ruled out that similar genome editing research for military purposes is already taking place: for instance, in a study CRISPR/Cas9 was classified as one of the three main technologies with the potential to enhance combat efficiency of soldiers.[21] There are also more concrete examples: some argue that China may have started human experimentation to develop a military with enhanced capabilities; in 2020, a team of U.S. army medical scientists began developing a gene therapy with the aim of protecting humans against G-type nerve poisons – in other words highly toxic chemicals that can cause paralysis and, in worst cases, death – for several weeks to months, and there are no U.S. rules forbidding the use of enhancement on soldiers.[22]

More broadly, it could be drawn a distinction between *risk* – which can be calculated – and *uncertainty*, when it is impossible to determine probabilities or the outcome is unknown; germline safety risk can be seen as primarily dependent on uncertainty, since there is not any knowledge about the risks without previous experiences.[23]

2.2 Consent and Autonomy of Future Generations

Although the safety one is one of the main issues to be taken into account, it is crucial not to limit the intricate procedure of ethical decision-making to this alone,[24] as suggested by the European Group of Ethics in Science and New Technologies:

[20] WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing, *Human genome editing: a framework for governance*, World Health Organization, Geneva 2021, p. 7.
[21] Badea A.R., Feeny O., *op. cit.*, pp. 102-103.
[22] *Ivi*, p. 103.
[23] Baumann M., *op. cit.*, p. 145.
[24] Almeida M., Ranisch R., *op. cit.*, p. 7.

> Whereas debates about genome editing often focus on the question '*how safe is safe enough?*', the EGE draws attention to the importance of nuancing and resisting this framing.[25] […]
>
> The 'safe enough' framing is reminiscent of the 'technological imperative', the notion that 'if it is technologically feasible then it ought to be done'. This eschews more ethically pressing questions such as whether genome editing is in fact necessary, acceptable, and under what conditions. To be clear, it is not that the technological imperative necessarily entails a 'safe enough' narrative, but capturing the attention with 'safe enough?' can lead to obfuscating other questions and indeed to making this one question the 'one door – one key' of technological roll-out. All of this under the guise of promoting sound decision making and shared value, with safety as (least or sole) common denominator.[26]

The EGE, as a matter of fact, goes back to the importance of those that we might consider – based on the classification presented in the previous paragraph – *categorial* aspects: concept such as humanness, naturalness and diversity, [27] since neither efficacy nor safety alone automatically imply that genome editing is aligned with ethical principles of a society or its cultural standards. [28]

Indeed, another concern strongly present in the debate about genome editing is the autonomy of the future generations:[29] some objections against GGE question the legitimacy of current individuals to make choices on behalf of future generations.[30] Joel Feinberg was the first one to theorize – originally, regarding religious education – the so-called 'right to an open future':

> When sophisticated autonomy rights are attributed to children who are clearly not yet capable of exercising them, their names refer to rights that are to be saved for the child until he is an adult, but which can be violated 'in advance', so to speak, before the child is even in a position to exercise them. The violating conduct

[25] *European Group on Ethics in Science and New Technologies opinion on the Ethics of Genome Editing*, Publications Office, 2021, https://data.europa.eu/doi/10.2777/659034, p. 20.
[26] *Ivi*, p. 21.
[27] *Ivi*, p. 24.
[28] Almeida M., Ranisch R., *op. cit.*, p. 7.
[29] *Ivi*, p. 9.
[30] Gyngell C., Douglas T., Savulescu J., *The Ethics of Germline Gene Editing*, "Journal of Applied Philosophy", 34:4 (2017), p. 507.

> guarantees now that when the child is an autonomous adult, certain key options will already be closed to him. His right while he is still a child is to have these future options kept open until he is a fully formed self-determining adult capable of deciding among them.[31]

Even though Feinberg originally developed this idea regarding the children's religious education, various authors applied it to the genetic intervention discussion, emphasizing the necessity that such procedures do not reduce the future possibilities of the offspring to freely shape their life according to their own choices.[32] In most modern societies, indeed, each person – including children – is granted the right to autonomy and self-determination, hence anyone has the right to make their own decisions that concern their body. The exercise of this right is protected, within healthcare system, through informed consent, a core principle of medical ethics involving human subjects,[33] which is generally required in both clinical and research contexts.[34]

There is not a universal formula regarding either the conditions where informed consent is required, nor what it entails, but it usually involves the sharing of relevant information, such as potential risks and benefits or alternatives. Furthermore, it implies that the person taking the decision agrees to proceed, giving their voluntary and informed consent;[35] typically, parents provide the authorization for both their children's medical care and their participation in research[36] and, more broadly, parents make decisions on behalf of their kids all the time, both before and after birth, and it is generally regarded as acceptable, so why shouldn't germline modifications be considered just another kind of modification, not that different from any other decision that parents routinely make?[37]

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[31] Feinberg J., *The Child's Right to an Open Future*, in W. Aiken, H, LaFollette (eds.), *Whose Child?*, Rowman & Littlefield, Totowa 1980, pp.125-126.
[32] Almeida M., Ranisch R., *op. cit.*, p. 9.
[33] *Ibid.*
[34] Wiley L., Cheek M., LaFar E., et al., *op. cit.*, p. 281.
[35] *Ibid.*
[36] *Ibid.*
[37] Smolenski J., *CRISPR/Cas9 and Germline Modification: New Difficulties in Obtaining Informed Consent*, "The American Journal of Bioethics", 15:12 (2015), p. 36.

First of all, typical parental decisions, such as education or other activities, may limit a child in certain ways, but do not entail irreversible consequences. The actual consequences of any germline editing intervention may be known not only once a modified embryo is transferred and implanted, but also through a long-term observation of what kind of impact that procedure has on the person who will grow. That is why allowing for such research could imply the subject's – and probably their descendants' too – commitment to a lifelong monitoring. And even though current consent procedure includes a so-called 'escape clause', which allows participants to withdraw from a research project, by the time a genetically modified person is able to revoke consent to the participation, the procedure will have already taken place with its permanent effects, that will also influence their offspring:[38] apart from opting out of monitoring, it is not clear what it would entail to withdraw from gene editing research, since there is no way to reverse the edits.[39] Hence, in this case the parents' intervention would lead to a permanent, irrevocable change in the child and their future descendants, and that is why these kinds of procedures cannot be assessed in the same way in which we evaluate those routinely parenting interventions.[40]

It is also worth noting that from the perspective of authors who adopt a cautiously critical view toward genome editing – who in the literature on this topic are often referred to as 'bio conservative' – edited human beings can be considered '*biofacts*', that is "a form of incarnate and living biotechnical design",[41] and this gives rise to a new kind of relationship between humans: the genetic designer and the genetically designed person; it would not be the first time that scientific developments reshape human relationships – consider, for example, surrogate pregnancies – so this fact alone does not indicate its moral value. At the same time, some critics contend that turning humans into biofacts by interfering with their

[38] Smolenski J., *op. cit*., p. 36.
[39] Wiley L., Cheek M., LaFar E., et al., *op. cit.*, p. 282.
[40] Smolenski J., *op. cit.*, p. 36.
[41] Primc N., Do *we have a right to an unmanipulated genome? The human genome as the common heritage of mankind*, "Bioethics", 34:1 (2020), p. 47.

DNA is an ethically problematic concept, since it would undermine their dignity and right to autonomy. This kind of position is often influenced by Habermas, who claims that genetic manipulation not only leads to an objectification of humans, but also poses a threat to the identity of the human species – an issue that will be addressed in the following paragraph – and to the autonomy of the edited individuals, who might no longer consider themselves as the only authors of their life.[42]

At the same time, however, it is important to highlight that the crucial question with GGE, as with any intervention that poses risks on individuals unable to give consent, is whether their expected well-being outweighs the potential dangers: in cases where parents give permission to genome editing interventions aiming to actually broaden the future life choices of their child, for example by removing a disposition to disease, the increase of autonomy given by the procedure can be regarded as outweighing the lack of informed consent from the child; it may be argued, in fact, that it is precisely the presence of the disease, rather than the gene editing, that constitutes a significant threat to their future autonomy.[43]

According to Habermas himself – which raises criticism especially in the context of enhancement and appears to be more tolerant about GGE to prevent critical diseases – it cannot be excluded that edited individuals, later in their life, will probably approve any prenatal procedures carried out to prevent serious illnesses for this exact reasons:[44]

> In the case of *therapeutic* gene manipulations, we approach the embryo as the second person he will one day be. This clinical attitude draws its legitimizing force from the well-founded counterfactual assumption of a possible consensus reached with another person who is capable of saying yes or no. the burden of normative proof is thus shifted to the justification of an anticipated consent that at present

[42] Primc N., *op. cit.*, p. 47.
[43] Gyngell C., Douglas T., Savulescu J., *The Ethics of Germline Gene Editing*, "Journal of Applied Philosophy", 34:4 (2017), p. 507.
[44] Primc N., *op. cit.*, pp. 47-48.

> cannot be sought. In the case of a therapeutic intervention in the embryo it might, in the best of cases, be confirmed later […].[45]
>
> In any case, *assumed* consensus can only be invoked for the goal of avoiding evils which are unquestionably extreme and likely to be rejected by all.[46]

Moreover, it can be argued that, as the potential harm would be amplified when any negative effect could be transmitted to future generations through GGE, also the potential benefits derived from it would be expanded; it could also be maintained that the benefits arising from it will spread across generations, whereas harms may not since, if any potential adverse effect occurs, it may encourage research to prevent its transmission or it could potentially be fixed.[47]

2.3 Human Genome Integrity

The issue of the legitimacy of genome editing falls within a broader philosophical debate – still continuing – on 'human nature', especially since its effects are heritable.[48]

The so-called 'bioconservatives' – those who maintain that GGE constitutes an ethical boundary that should not be crossed, even if sufficiently safe – argue that one of the main arguments to forbid genome engineering is that its modifications are inherently wrong, due to the unique status of the human genome,[49] which is regarded by many as central to the definition of 'human nature' and as safeguarding the unity of the human species.[50] This position also appears to be supported by official institutions such as UNESCO, to the extent that in its Universal Declaration on the Human Genome and Human Rights it is declared that

> The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.[51]

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[45] Habermas J., *The Future of Human Nature*, Polity Press, Cambridge 2003, p. 43.
[46] *Ibid*.
[47] Smith K.R., Chan S., Harris J., *Human Germline Genetic Modification: Scientific and Bioethical Perspectives*, "Archives of Medical Research", 43 (2012), p. 505.
[48] Almeida M., Ranisch R., *op. cit.*, p. 8.
[49] Primc N., *op. cit.*, p. 41.
[50] Almeida M., Ranisch R., *op. cit.*, p. 8.
[51] UNESCO, *Universal declaration on the human genome and human rights*, UNESCO, Paris 1997, p. 42.

Because of this way of viewing the human genome, as an 'heritage' that needs to be protected, according to opponents of GGE it risks to be jeopardized by genetic engineering: since GGE introduces changes that, as we saw, can be passed on to future generations, it constitutes a threat to the unity and identity of the human species, as these modifications on the long term would impact the human gene pool, thus influencing the evolutionary pathway of the human species.[52] As a matter of fact, due to the complexity of gene frequency and microevolution, it is impossible to manage or even predict the impact of modified genes in future generations.[53]

This argumentation, however, is not free from flaws: the idea of preserving the human genome in its current state presupposes its stability, but several authors have commented on the intrinsic dynamism of the genome, which has naturally been subjected to changes, as shown by human evolution. Every individual's genome, as a matter of fact, naturally undergoes occurring mutations, since studies have shown that, on average, each human genome carries 60 new mutations with respect to their parents; most of these do not seem to be affect the subject's health neither positively nor negatively, while some may be unfavourable to their well-being.[54]

At the population level, a 'standard' human genome can contain approximately 4,1 – 5 million variants in comparison to the 'reference' genome. Taking all of this into account, it can be stated that the 'reference' genome is a kind of statistical entity, that represents the probability distribution of various gene variants across the entire genome: human genomic adjustments underlie the differences in the variety of physical traits that can be observed in humans, such as eye colour, height ecc., and in certain genetic diseases, so different sets of genomes can be found among the human population, rather than a unique human genome that must be safeguarded.[55]

[52] Almeida M., Ranisch R., *op. cit.*, p. 8.
[53] Rubeis G., Steger F., *op. cit.*, p. 136.
[54] Almeida M., Ranisch R., *op. cit.*, p. 8.
[55] *Ibid.*

From an evolutionary biology perspective, thus, it is essential for humans to have mutable genome, since genetic diversity allows our species to adjust to the current environment and to different conditions, so mutations are not flaws and do not automatically entail negative outcomes; on the contrary, they represent an intrinsic and major component of our species' evolutionary development:[56] as the physician Lewis Thomas wrote,

> The capacity to blunder slightly is the real marvel of DNA. Without this special attribute, we would still be anaerobic bacteria and there would be no music. Viewed individually, one by one, each of the mutations that have brought us along represents a random, totally spontaneous accident, but it is no accident at all that mutations occur; the molecule of DNA was ordained from the beginning to make small mistakes.[57]

Nevertheless, even though the idea of a distinctive human genome can be questioned from a biological point of view does not automatically imply that genome editing is permissible. It is, in fact, important to recognize that the relevance of human genome integrity can be interpreted from a different perspective: a symbolic one, according to which what matters is not the stability of the genome over time, but rather the distinction between variations that occur naturally and those that are artificially induced. This argument is hence based more on the 'natural vs unnatural' distinction, than on an assertion in favour of an unaltered genetic sequence.[58]

Furthermore, this kind of discussion is based on the claim that the 'naturally' evolved genome represents a central element in the concept of human nature, but in which way can human nature be defined? This question is, of course, part of a wider discussion and it cannot be answered in a definitive way, but it can be helpful to distinguish between an empirical and a non-empirical application of this term: in a non-empirical, metaphysical sense, it can indicate a universal and distinct human essence, which in this context is defined by a set of features and skills that

[56] Coller B.S., *Ethics of Human Genome Editing*, "Annu Rev Med", 70 (2019), p. 5
[57] Thomas L., *The Medusa and the Snail*, Viking, New York 1979, p. 23.
[58] Almeida M., Ranisch R., *op. cit.*, p. 8.

should distinguish humans from other living beings and cannot be fully described empirically.[59]

In a strictly empirical sense, however, the term 'human nature' refers to the totality of the empirically observable traits of human beings; it cannot be referred to an immutable essence of human beings since, from the perspective of evolutionary biology, empirical traits are the result of natural selection and it is important to keep in mind that any biomedical intervention in human subjects constitutes an intervention on human nature in this empirical sense.[60] The idea that our empirical nature is primarily defined by the genome has widely faced criticism on several grounds, the most common of which is that it seems to imply a tendency to promote genetic determinism or reductionism, thus overemphasizing the role of genes in the shaping of phenotypic traits.[61] Contemporary biomedical science, on the contrary, has moved into the so-called 'post-genomics' era, which shows a shift in the main line of research from genetic information to other biological components, such as protein functions and metabolic processes.[62]

The supporters of the human germline as safeguarding the unity of the human species not only argue that this is a normative intrinsic value, but also that it ensures a continuity among different generations. Still, interventions on heritable genome do not imply a sharp break of this continuity: when procedures such as CRISPR/Cas9 occur, the whole human genome is not replaced with an artificial one, there only are modifications of restricted areas of DNA so the genome remains unedited for the most part – at least, in operations for therapeutic purposes.[63] Different considerations could arise in the case of genetic enhancement, which may introduce new trait; however, as long as GGE interventions are aimed only to the prevention of severe genetic diseases, they should not result in sudden fractures in the transmission of the human lineage.[64]

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[59] Primc N., *op. cit.*, p. 45.
[60] *Ivi*, pp. 44-45.
[61] Primc N., *op. cit.*, p. 45.
[62] *Ibid.*
[63] *Ivi*, p. 46
[64] *Ibid.*

In any case, as the consequences of this kind of technology will propagate across several generations, it is important to evaluate the risks that humanity as a whole is inclined to accept in order to manage certain disease and advance health. To carry out this type of evaluation, it is necessary to examine social perspectives, cultural norms and values related to the human genome, in addition to any potential perception that technology may be manipulating 'nature'.[65]

[65] Almeida M., Ranisch R., *op. cit.*, p. 8.

Chapter 3 - de Melo-Martín: Attending to Justice

3.1 Procreative Liberty in Relation to Justice

Across the literature on this matter, a range of various terms can be found in relation to the concept of reproductive autonomy, such as 'reproductive choices', 'reproductive rights' or 'procreative liberty', and all of them presuppose a fundamental assumption:[1] reproductive choices are widely regarded as central to an individual's identity and as a crucial element in their life plans, hence it seems reasonable to safeguard them from any form of interference.[2] However, to accept that reproductive liberty results in the right to have children does not imply that even the right to have a specific child exists,[3] which according to Inmaculada de Melo-Martín is exactly the goal of what she calls '*reprogenetics*' technologies, that can be defined as "practices that combine reproductive technologies and genetic tools".[4] Reprogenetics, in fact, are not intended to merely help individuals in having children, but to select or create embryos with particular traits valued by the parents.[5]

Generally, advocates of reprogenetics justify their support to these technologies based on a rights-based liberal perspective, according to which reproductive choices and autonomy are fundamental freedoms, hence any interference with them can only be justified if such parental decisions severely harm others' well-being.[6]

de Melo-Martín criticizes this very perspective, highlighting how many reprogenetics proponents take for granted, rather than accounting for it, the idea that those technologies fall within the sphere of procreative liberty.[7] She does not

[1] Johnston J., Zacharias R.L., *The Future of Reproductive Autonomy*, "Hastings Center Report" 47:6 (2017), p. S8.
[2] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, Oxford University Press, Oxford 2017, p. 62.
[3] *Ivi*, p. 63.
[4] *Ivi*, p. 35.
[5] *Ivi*, p. 63.
[6] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 63.
[7] *Ibid.*

only consider inadequate the claim that reproductive freedom implies the right to use reprogenetic technologies to select or enhance one's offspring, but also asserts that even if that claim is accepted, the proponent's argument that reprogenetics do not cause any demonstrable harm fails to persuade.[8]

As a matter of fact, one of the most disputed factors of reprogenetic technologies is their potential use for the selection or editing of genetic traits unrelated to diseases, including sex, hair or skin colour and height.[9]

According to a thesis common to many, as mentioned earlier, reproductive freedom would simply be the result of people's interest in taking choices according to their own values; consequently, there would be no need to regard it as a fundamental right but, given the broadly accepted view that choices within the reproductive field are highly significant for people's lives, any restriction on such decisions should be supported by strong justifications.[10] This appears to gather the position adopted by two particularly influential authors that support the use of reprogenetics, John Harris and Julian Savulescu;[11] in particular, Harris refers to this as the '*democratic presumption*' that is, in his own words, "that human freedom will not be constrained unless very good and powerful reasons can be produced to justify such infringement of liberty".[12]

Yet, as de Melo-Martín observes, in these authors' writings a considerate justification for this notion is lacking, and the 'democratic presumption' seems to be taken for granted; even granting that it is accepted in relation to private decisions, the extension of this 'right' to public decisions requires the provision of strong arguments.[13] Moreover, de Melo-Martín argues that reproductive choices, especially those involving reprogenetic technologies, cannot be treated as entirely

[8] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 63.
[9] *Ivi*, p. 64.
[10] *Ivi*, p. 74.
[11] *Ibid.*
[12] Harris J., *Sex selection and regulated hatred*, "Journal of medical ethics" 31:5 (2005), p. 291.
[13] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 75.

private matters, not least because the development of those techniques implies funding and the involvement of health professionals and scientists.[14]

This does not entail that there is not a right to reproduce or that reproductive choices should not be protected from unwarranted interference, but it demonstrates that reprogenetics advocates have not provided persuasive – or, in some cases, any – arguments in support of the claim that the right to reproduce includes the right to bring into existence a *particular* child.[15]

More specifically, in the case of gene editing interventions the purpose of reprogenetic technologies cannot be intended as simply helping people have healthy children, since there already are many options available to prospective parents who are at risk of transmitting disease-related mutations (for example adoption and gamete and embryo donation), so according to de Melo-Martín the assumed added value of techniques such as CRISPR for the potential parents is the possibility of having genetically related children.[16] Even accepting the thesis that assisting individuals in having genetically related children constitutes a priority, de Melo-Martín argues that the pursuit of this goal through the development of reproductive genome editing should not rely on public resources, in light of justice-related concerns.[17]

The main argument she proposes in support of this claim is that RGE is likely to benefit only a remarkably low number of potential parents, since for example the US genetic epidemiological data indicates that the number of individuals for whom embryo editing would constitute the sole possibility to have healthy and genetically related children is just a few hundred, provided that all of them would chose to rely on this kind of intervention.[18] It is true that, as noted in chapter one, the fact that only a limited number of subjects would benefit from this technology

[14] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 76.
[15] *Ibid*.
[16] de Melo-Martín I., *Reproductive Embryo Editing: Attending to Justice*, "Hastings Center Report" 52:4 (2022), p. 27.
[17] *Ivi*, p. 28.
[18] *Ivi*, p. 29.

does not, by itself, provide a sufficient justification to consider it illegitimate; however, de Melo-Martín's argument here is not concerned with the legitimacy of this technology per se, but rather with the motives, from the perspective of social justice, why such interventions should not be supported by public fundings.

On the other hand, investing in research on both pregnancy and early childhood, removing obstacles to pre- and postnatal healthcare, guarantying access to proper nutrition for potential mothers and their children and improving social and environmental support system could allow millions of families to fulfil their desire to have healthy and genetically related children.[19]

Moreover, as de Melo-Martín observes, even in wealthy countries, racial and ethnic minorities are systematically disadvantaged in terms of the possibility of achieving the same goal:[20] treatments other than CRISPR range in cost from 450.000 to 2 million dollars, while CRISPR therapies can cost up to 3.5 million dollars; such costs obviously make these kinds of interventions unaffordable for most people and in particular for marginalized communities which, in addition to economic limitations, face not only limited access to advanced therapies, but also lower awareness about them.[21]

In order to carry out RGE procedures it is necessary to first undergo the IVF process, a kind of procedure which is definitely high-priced and in countries such as the United States, where the healthcare sector is mainly private, access to IVF and other genetic services primarily relies on the individual's economic resources,[22] meaning that the majority of individuals who would actually benefit from these interventions would be white.[23]

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[19] de Melo-Martín I., *Reproductive Embryo Editing: Attending to Justice*, "Hastings Center Report" 52:4 (2022), p. 29.
[20] *Ibid*.
[21] Gibelli F., Ricci G., Bailo P., *Genome Editing in Medicine: A Scoping Review of Ethical, Bioethical, and Medico-Legal Implications*, "Journal of Law, Medicine & Ethics" 53:1 (2025), p. 110.
[22] de Melo-Martín I., *On our obligation to select the best children: a reply to Savulescu*, "Bioethics" 18:1 (2004), p. 74.
[23] de Melo-Martín I., *Reproductive Embryo Editing: Attending to Justice*, "Hastings Center Report" 52:4 (2022), p. 29.

In conclusion, de Melo-Martín claims that the acknowledgement that science and technology are crucial to improve the living standards and human capacities, coupled with the fact that poorer populations are far less likely to get those benefits, provides the basis for the argument that access to benefits of scientific advancements should be recognized as a universal human right.[24]

However, these kinds of argument are insufficient: de Melo-Martín focuses on a US-centric generalisation in discussing health related issues, but neglects to consider that in public health systems this line of reasoning fails. In England, for instance, the national guidelines from the NICE (National Institute for Health and Care Excellence) offer funding for three full cycles of IVF to women who meet the criteria required;[25] in France, assisted reproduction procedures are fully funded by health insurance up to four cycles for eligible subjects (heterosexual couples, female couples or unmarried woman).[26] Also in Italy assisted reproductive technology is now part of the 'Essential Levels of Assistance' (LEA) and it is thus recognised as one of the services guaranteed by the National Health Service, providing up to six ARTs cycles for women who meet the established criteria.[27] These are just a few examples, but they help illustrate that, within the context of publicly funded healthcare, the exacerbation of inequalities presumed by de Melo-Martín is far from given. Ronald Green, an American scholar, goes as far as to say that, as other advanced technologies, germline gene interventions might actually lower overall healthcare costs providing cutting-edge, more effective solutions rather than expensive temporary treatments,[28] while many other scholars highlight

[24] De Melo-Martín I., *Reproductive Embryo Editing: Attending to Justice*, "Hastings Center Report" 52:4 (2022), p. 29.
[25] National Institute for Health and Care Excellence, *Quality Statement 5: IVF for Women under 40 years*, NICE (2014), https://www.nice.org.uk/guidance/qs73/chapter/quality-statement-5-ivf-for-women-under-40-years, accessed February 15, 2026.
[26] Caisse Nationale d'Assurance Maladie, *Prise en charge de l'assistance médicale à la procréation (AMP)* (2026), https://www.ameli.fr/assure/remboursements/rembourse/assistance-medicale-la-procreation-amp/prise-en-charge-de-l-assistance-medicale-la-procreation-amp, accessed February 15, 2026.
[27] IBSA Italy, *Assisted Reproductive Technology joins the new Essential Levels of Assistance: a step forward for Italian couples*, IBSA Italy (2025), https://www.ibsaitaly.it/en/media/news/2025/la-procreazione-medicalmente-assistita-entra-nei-nuovi-lea.html, accessed February 15, 2026.
[28] Green R.M., *Babies by Design. The Ethics of Genetic Choice*, Yale University Press, New Heaven and London 2007, p. 137.

that international guidelines could help address issues of these kinds, guaranteeing fair access to gene editing technologies.[29]

More broadly, with regard to gene editing various scholars emphasize that the risk of deepening already existing social inequalities may occur only if gene editing will be employed with the aim of human enhancement – which opens a broader debate, not fully aligned with the one about genetic intervention – but it is difficult to imagine that using genetic engineering to prevent diseases would result in consequences[30] such as those outlined by de Melo-Martín. Consequently, the need to ensure that the benefits of gene editing are fairly allocated should not result in a ban on the technology or impede its progress; rather, it draws attention to the necessity of making sure these techniques are developed responsibly.[31]

de Melo-Martín also takes into account some objections that could be advanced against her thesis; for instance, the one according to which as RGE's technology advances its application could expand to serve a much bigger number of families, potentially to help prevent less severe genetic condition, or in addition to other technological alternatives, hence changing its very target: from helping people having a healthy offspring with a biological relationship with their parents, to improving the whole human species.[32]

She replies to this objection that it is not sufficient to support the social funding for RGE: the analysis of a technology's risks and benefits is necessarily tied to its intended purpose.[33] So it is one thing to argue that the use of RGE is worth the associated risks because there is no other alternative; it is quite another to evaluate a technology aimed at helping people avoid transmitting minor disease, or to

[29] Kannan S., Najjar D., *Therapeutic gene editing is here, can regulations keep up?* "MIT Science Policy Review" 1 (2020), p. 69.
[30] Gyngell C., Douglas T., Savulescu J., *The Ethics of Germline Gene Editing*, "Journal of Applied Philosophy", 34:4 (2017), p. 509.
[31] Gyngell C., Bowman-Smart H., Savulescu J., *Moral reasons to edit the human genome: picking up from the Nuffield report*, "Journal of Medical Ethics" 45:8 (2019), p. 521.
[32] De Melo-Martín I., *Reproductive Embryo Editing: Attending to Justice*, "Hastings Center Report" 52:4 (2022), p. 31.
[33] *Ivi*, p. 32.

enhance someone's child – a purpose which is, in itself, ethically questionable[34] for several reasons, some of which were outlined in the previous chapter.

3.2 The Illusion of Control

As de Melo-Martín notices, it is often cited as a reason for the use of reprogenetics their supposed ability to overcome the inevitable randomness in the 'natural lottery' of standard human reproduction, which is regarded as intrinsically flawed by proponents of reprogenetic technologies.[35] The philosopher draws specifically on Savulescu and Harris,[36] who claim that

> Not only is natural reproduction inefficient, it is also unsafe. Approximately 3-5% of babies born have some abnormality. Natural reproduction not only involves the foreseeable and unavoidable creation of some embryos that will die but also some embryos that will go on to become very disabled human beings. Many embryos created are so genetically abnormal that they die, but some survive only to die as grossly deformed babies.[37]

She also observes that advocates of reprogenetics often oppose the risks entailed in sexual reproduction with the safer outcomes promised by ARTs, as well as its unpredictability with the rational control they believe the latter provide, as it is again evident in what Savulescu writes:[38]

> Our future is in our hands now, whether we like it or not. But by not allowing enhancement and control over the genetic nature of our offspring, we consign a person to the natural lottery, and now, by having the power to do otherwise, to fail to do otherwise is to be responsible for the results of the natural lottery. We must make a choice: the natural lottery or rational choice. Where an enhancement is plausibly good for an individual, we should let that individual decide. And in the

[34] *Ivi*, pp. 31-32
[35] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 133.
[36] *Ibid*.
[37] Savulescu J., Harris J., *The Creation Lottery: Final Lessons from Natural Reproduction: Why Those Who Accept Natural Reproduction Should Accept Cloning and Other Frankenstein Reproductive Technologies*, "Cambridge Quarterly of Healthcare Ethics" 13:1 (2004), p. 92.
[38] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 134.

> case of the next generation, we should let parents decide. To fail to allow them to make these choices is to consign the next generation to the ball and chain of our squeamishness and irrationality.[39]

de Melo-Martín then draws attention to a concerns that she claims arises directly from reprogenetics proponents' own estimation of human wisdom, which is an opinion that possibly reveals a tension, if not a total inconsistency, in some of their claims: on the one hand, they argue that humans could 'design' through reprogenetics their descendants better than sexual reproduction, escaping the potential 'mistakes' of natural selection and, as we have seen, this is an argument frequently used in support of ARTs to illustrate how this form of control may benefit our lives and, over the long run, positively impact society.[40]

On the other hand, however, some of the same proponents of reprogenetics also seem to claim that our power to manipulate nature and ourselves could ultimately lead to the destruction of our planet, to the extent that they argue that an additional form of enhancement – namely moral bioenhancement – is necessary to prevent the improvement of our cognitive faculties and current scientific developments, both human-designed, from becoming a threat to humanity, as stated by Persson and Savulescu:[41]

> The human species, and the rest of life on Earth, faces a series of disastrous threats. Some of these have been with us throughout our whole history. Scientific progress has helped us to protect ourselves against some of these, and will probably help us to protect ourselves against more in the future. But the irony is that the very same progress creates other equally lethal threats. […] in order to reduce the existential threat that cognitive enhancement poses, we require a moral enhancement, an enhancement of our motivation to act morally. The threats come not only from cognitive enhancement by novel biomedical and genetic means, but also from the growth of knowledge by traditional cultural means, and by external

[39] Savulescu J., *New breed of humans: the moral obligation to enhance*, "Reproductive BioMedicine Online" 10 (2005), p. 39.
[40] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 137.
[41] *Ivi*, p. 138.

means, such as access to supercomputers. Indeed, it may be that we already are too cognitively advanced for our own good (and for the good of other species on Earth).[42]

Precisely in relation to this, de Melo-Martín argues that the thesis that humans, which were imprudent enough to threaten the existence of their own species, should be relied upon to control reproduction and designing future generations is far from obvious: how can we take for granted that they could affect evolution in a responsible and beneficial way?[43]

It could be argued that the 'natural lottery' is what led to our existence, with all our recklessness, but de Melo-Martín claims it is far from evident that we could be more successful than the natural reproduction in bringing into the world wiser individuals.[44]

Moreover, the reprogenetic technologies are often portrayed as seamlessly progressing from detecting specific genetic mutations or variants or from editing an embryo's genome to determining whether that future child will possess certain phenotypic traits, but de Melo-Martín notices that the shaping of a human being and the trajectory of evolution are influenced by a range of factors that are not limited to the genetic ones.[45]

Although many reprogenetics advocates explicitly reject genetic determinism, it can be difficult to see how their arguments for regulating the design of future children could make sense without implying at least some form of determinism, since the degree of control that these technologies are supposed to provide requires for such practices to have fully reliable and predictable outcomes.[46] In fact, as partially discussed in the previous chapter, current scientific evidence disputes any deterministic view of human biology, showing instead that the occurrence of

[42] Persson I., Savulescu J., *The Perils of Cognitive Enhancement and the Urgent Imperative to Enhance the Moral Character of Humanity*, "Journal of Applied Philosophy" 25:3 (2008), p. 167.
[43] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 139.
[44] *Ivi*, pp. 139-140.
[45] *Ivi*, p. 140.
[46] *Ivi*, p. 145.

human phenotypic traits is not simply limited to individual genetic markers; indeed, the influence of genetic factors on complex traits is neither necessary nor sufficient to determine their presence.[47]

Portraying human traits as solely determined by our genetic asset also restricts the range of solutions available for the issues that reprogenetic technologies aim to address, since the main intent of these technologies should be a contribution to the advancement of human well-being.[48]

In addition to this, in the case of genome-editing techniques, even if they were employed to target specific genetic mutations associated with diseases or disabilities, they would exert only a limited effect on the recombination processes of the sexual reproduction.[49] When applied prior to conception, in fact, these technologies might fix certain unwanted recombinations, but they would not be able to regulate the errors that appear during the fertilization process; if applied when the embryos have already been created, they could only deal with the genetic conditions discernable at that stage.[50] It is true that, in theory, it would be possible to employ gene editing in both phases, yet in the light of multiple challenges, some of which have already been outlined, according to de Melo-Martín the allocation of resources with the presumed intention to control the 'natural lottery' is not to be taken for granted.[51]

Another important aspect brought to attention by de Melo-Martín is that, at present, it cannot be known for sure if gene editing interventions will result in birth defects or any other health issue, but the complexity of human biology makes such risks conceivable.[52]

de Melo-Martín concludes that the argument that reprogenetic methods offer a more rational and desirable way to create human beings and guide their evolution

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[47] *Ivi*, pp. 146-147.
[48] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 152.
[49] *Ivi*, p. 142.
[50] *Ibid*.
[51] *Ibid*.
[52] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 142.

is objectionable and illusory; and that, even if this kind of control were valuable, it could not be fully reached through the application of these technologies.[53]

At the same time, however, it could be argued that modern medicine necessarily entails an interference in natural processes, and consequently some degree of control over them; therefore, one may wonder why technologies such as gene editing should not be allowed, when intruding in the course of nature is widely accepted and approved for other established practices.[54]

3.3 Gender-Neutral Approach: a Grave Oversight

Feminist scholars have consistently emphasized that science and technology are hardly ever neutral with respect to gender,[55] since they both have distinct consequences for men and women,[56] so treating reprogenetics technologies under the assumption of gender neutrality is problematic and unjustified for several reasons.[57]

Women's bodies and reproductive cells are indeed fundamental to the improvement and application of reprogenetic technologies.[58] While some bioethicists, such as Harris or Savulescu, in addition to supporting for this kind of interventions also maintain that there may exist a moral obligation to pursue its development and application in order to improve the well-being of our children, de Melo-Martín firmly opposes to this argument, suggesting that in most cases, if not all, a better option may lie in social or political measures, rather than technological treatments.[59] The problem that she highlights in the ethical debate about reprogenetics is, in fact, that it fails to take into account all aspects that are

[53] *Ivi*, p. 154.
[54] Rubeis G., Steger F., *Risks and benefits of human germline genome editing: An ethical analysis*, "Asian Bioethics Review" 10 (2018), p. 138.
[55] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 165.
[56] *Ivi*, p. 166.
[57] *Ivi*, p. 168.
[58] *Ivi*, p. 160.
[59] Hauskeller M., *Rethinking Reprogenetics*, "Hastings Center Report" 47:2 (2017), p. 50.

genuinely relevant,[60] slipping into the so-called 'safe enough narrative'[61] mentioned in the previous chapter.

Nonetheless, influential advocates rarely – if ever – address women's role in any relevant way when supporting these technologies, seeming entirely unaware of the burdens that they place on women's health and lives.[62] Women, in fact, carry an unfairly large amount of the risks and burdens arising from the use of reprogenetics,[63] but the works of the leading proponents of these technologies lack an analysis that actually takes gender into account as a significant factor.[64]

Discussions about reprogenetics indeed focus on infertile couples, gamete donors or parental rights and obligations, but women are rarely mentioned: de Melo-Martín cites, for instance, DeGrazia[65], who in his study on prenatal genetic interventions points out that these procedures require IVF – a factor that might limit their application – but he neglects to examine the implications of the need for IVF.[66] However, DeGrazia is not an isolated case: as de Melo-Martín points out, women not only are frequently overlooked in the ethical debate on reprogenetics, but when they are mentioned it is in a superficial way, without paying much attention to their responsibilities and the potential risks they face.[67] In most cases, discussions of these technologies assume their use is legitimate when safety and efficacy can be granted, thus failing to acknowledge that, besides any unpredictable consequence, reprogenetics will for sure entail well-established risks for women: it is true, naturally, that reproductive decisions are made by 'couples'

[60] *Ibid*.
[61] *European Group on Ethics in Science and New Technologies opinion on the Ethics of Genome Editing*, Publications Office, 2021, p. 21.
[62] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 161.
[63] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 160.
[64] *Ivi*, p. 161.
[65] DeGrazia D., *Creation ethics: reproduction, genetics, and quality of life*, Oxford University Press, New York 2012.
[66] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, Oxford University Press, Oxford 2017, pp. 162-163.
[67] *Ivi*, pp. 163-164

or ‘reproducers’, yet it is women alone that get pregnant[68] and solely women who have to undergo IVF and its impact.[69]

In addition to this, it is equally important to highlight that reprogenetics technologies also affect women differently based on the social context they experience: in the United States, where – as is well known – access to medical technologies is widely determined by one’s ability to pay, it has been shown that white, economically privileged women represent the primary users of these tools.[70] By contrast, as evidenced by the expanding market for cross-border reproductive services, it is often financially disadvantaged women who provide eggs and act as gestational carriers. Moreover, while white, middle-class women receive support for the use of these technologies, various institutional practices hinder women of colour from having children.[71]

Similarly, one of the main goals of reprogenetics is – as will be discussed more thoroughly in the next chapter – the prevention of the birth of children with certain disabilities or health conditions, which makes women’s pregnancies at higher risk to result in children with disabilities a target group.[72]

Although it is important to take into account the intersectionality of gender with other social categories such as race, disability, class or nationality, this does not imply that gender itself is negligible.[73]

de Melo-Martín draws attention to how IVF treatments pose several health risks for women in each phase, starting from the fertility drugs prescribed to induce ovulation up to the egg retrieval procedures. Moreover, in comparison with natural conception IVF has been shown to indicate a considerably higher risk of ectopic pregnancy, that is a pregnancy characterized by the implantation of the embryo outside of the uterus; this kind of pregnancy occur in 1% to 2% of the general

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[68] *Ivi*, p. 176.
[69] *Ivi*, p. 164
[70] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 168.
[71] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., pp. 168-169.
[72] *Ivi*, p. 169.
[73] *Ivi*, p. 169.

population, while its incidence raises from 2% to 11% after IVF. Ectopic pregnancies can lead to rupture, causing internal bleeding, pelvic and abdominal pain and, in some extreme cases, death.[74]

Furthermore, the transfer of more than one embryo often leads to multiple pregnancies, which involve additional risks both for the women and the babies.[75]

Beyond the health risks women may face when they undergo these procedures, which falls outside the extent of this thesis, decisions regarding the use of reprogenetics have morally significant different effects on men and women and, as previously noted, they subject women to unequal burdens. Proponents of reprogenetics often invoke the rhetoric of choice to justify these technologies, but their gender-neutral discussion overlooks how the presumed increase in individual choice may actually limit the options available to many women, thereby affecting their social status.[76]

As de Melo-Martín notes, to assume that having many options is inherently positive means to view the individual as completely separate and independent from broader power structures and to abstract their choices from the situation in which they take place. The assumption that having more choices is in itself better actually overlooks the importance of the social and political circumstances in which those options are offered, as well as how the socio-political context not only shapes the decision-making process, but also determines who can make those choices and what can be chosen.[77]

In general, paying proper attention to the consequences of reprogenetics on women does not merely entail rejecting it or considering it illegitimate; however, even if selection and enhancement techniques were considered permissible and useful for the purpose of social progress, accounting for their negative impact on women

[74] *Ivi*, pp. 170-171.
[75] *Ivi*, pp. 171-172.
[76] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., pp. 172-173.
[77] *Ivi*, pp. 175-176.

would still contribute to a more responsible and mindful implementation of reprogenetics.[78]

These considerations are important because technologies are not value-neutral: many studies have demonstrated that the notion of 'value-neutrality' cannot be applied to science and technology;[79] rather, they reflect certain values and have an influence on others and on how we understand and interact with the world.[80] In general, science primarily aims to not merely discover facts about the world, but to identify those truths that are considered meaningful, an evaluation necessarily made in relation to human values and concerns;[81] in certain instances, the creation and development of a technology can also reinforce or exclude specific political values.[82]

Technologies not only influence what we consider to be valuable, but also how strongly we value it; the normative judgements we use to analyse technologies are formed in conjunction with them, progressing alongside their development and implementation.[83]

In particular, according to de Melo-Martín reprogenetics exemplify this value-ladenness by presenting questions regarding health diseases and disability as matters concerning individuals.[84]

It is crucial to emphasize the value-laden character of reprogenetics for a number of reasons: framing those issues as individual interests results in abstracting them from their wider social context and, consequently, neglecting potential collective solutions, even though questions such as health, disease and disability from de

[78] *Ivi*, p. 184.
[79] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 207.
[80] de Melo-Martín I., *Valuing Reprogenetic Technologies: Bringing Insights from the Philosophy of Technology to Bioethics*, in Laspra B., López Cerezo J. (eds.), *Spanish Philosophy of Technology*, Springer, Cham 2018, pp. 50-51.
[81] de Melo-Martín I., *Rethinking Reprogenetics. Enhancing ethical analyses of reprogenetic technologies*, cit., p. 208.
[82] *Ivi*, p. 210.
[83] de Melo-Martín I., *Germline Gene Editing: Minding the Past and the Future*, "The American Journal of Bioethics" 20:8 (2020), p. 37.
[84] de Melo-Martín I., *Valuing Reprogenetic Technologies: Bringing Insights from the Philosophy of Technology to Bioethics*, in Laspra B., López Cerezo J. (eds.), *Spanish Philosophy of Technology*, Springer, Cham 2018, p. 51.

Melo-Martín can, and often should be addressed collectively – especially since it is precisely the social context in which they are situated that largely determines whether certain traits may pose a disadvantage for an individual's quality of life.[85] At the same time, it is worth noting that the value-ladenness argument can be used to either support or reject any technology, for instance it is clear that supporters of genetic engineering regard it as a source of positive innovation and beneficial developments for human health.

According to de Melo-Martín, assessments of reprogenetic technologies that only focus on risk/benefit analysis are bound to neglect the ways in which the application of these technologies may wrongfully shift attention and resources away from the social, political and economic aspects that profoundly affect overall health.[86] Since genetic factors constitute just one part within the composite whole of influences on wellbeing outcomes, neglecting the bigger social determinants of health is likely to exacerbate people's quality of life.[87]

The pursuit of a more comprehensive, justice-oriented approach to reproductive autonomy can definitely be challenging, since it requires confronting deeply rooted and politically charged issues like poverty and discrimination.[88]

However, engaging with a more comprehensive grasp of reproductive choices, mindful of the bigger context, is essential to respect individuals: a future shaped by persistent economic and social inequalities and emerging reproductive technologies requires a more nuanced understanding of this kind of autonomy, which needs to be understood as a deeply contextualized process.[89] Such an approach seeks to enable actually free and informed decisions, that align with

[85] *Ibid.*
[86] *Ivi*, p. 52.
[87] de Melo-Martín I., *Valuing Reprogenetic Technologies: Bringing Insights from the Philosophy of Technology to Bioethics*, in Laspra B., López Cerezo J. (eds.), *Spanish Philosophy of Technology*, Springer, Cham 2018, p. 52.
[88] Johnston J., Zacharias R.L., *The Future of Reproductive Autonomy*, "Hastings Center Report" 47:6 (2017), p. S10.
[89] *Ibid.*

people's values although acknowledging not only the potential increase in reproductive choices, but also the limitations that come with them.[90]

de Melo-Martín's arguments could be considered legitimate, but rather weak: she makes no distinction between *de jure* considerations, that address questions of moral permissibility and normative justification of a practice, and *de facto* reflections, that is empirical conditions surrounding it, such as the social context. While the former can question the practice as such, regardless of the circumstances in which it is applied, the latter are contextual and can potentially be mitigated through regulatory frameworks and governance; therefore, *de facto* considerations such as those outlined by de Melo-Martín are not sufficient to assess gene editing as ethically illegitimate. What her arguments show, in fact, is that the real problem lies in the lack of adequate social preparedness: as some researchers from Harvard University observe, germline gene editing "in the long run will almost certainly be highly beneficial", therefore the debate should focus more on the question of how – in the light of critical issues such as those identified by de Melo-Martín – the scientific community can effectively regulate itself and on the need for a solid oversight framework, implemented on a global scale.[91] It would, in fact, appear more reasonable that concerns of social nature lead to transformations at the societal level, rather than a prohibition of the technology in question.

[90] *Ibid.*

[91] Bergman M., *Perspectives on Gene Editing*, The Harvard Gazette (2019), https://news.harvard.edu/gazette/story/2019/01/perspectives-on-gene-editing/, accessed February 17, 2026.

Chapter 4 - Gene editing and disability

4.1 The Medical, Social and Human Rights Models of Disability

As it has partially been seen, the exponential progress achieved in recent years in the field of biotechnologies and their (lack of) regulation raises a series of ethical, social and legal issues, especially with regard to the disability human rights movement.[1] This is an extremely vast debate, that also involves a discussion of concepts such as normality and human dignity. On the one hand, according to many a misuse of these technologies may lead to a '*slippery slope*' toward a new eugenics movement, but on the other hand they open up possibilities for new horizons for the human species.[2]

It is not simple to understand how such progresses in genetic engineering might affect people with disabilities; in 2015, the UN International Bioethics Committee highlighted the importance of keeping the tragic consequences of 20th Century eugenics movements and the ethical implications of gene editing distinct, but also asserted that[3]

> It impinges upon the principle of respect for human dignity in several ways. It weakens the idea that the differences among human beings, regardless of the measure of their endowment, are exactly what the recognition of their equality presupposes and therefore protects. It introduces the risk of new forms of discrimination and stigmatization for those who cannot afford such enhancement or simply do not want to resort to it. The arguments that have been produced in favour of the so-called liberal eugenics do not trump the indication to apply the limit of medical reasons also in this case.[4]

The intricacy of this wide debate is further intensified by the fact that people with disabilities, along with their families and caregivers, experience their human condition in several diverse ways.[5] Consequently, even with regard to these

[1] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 2.
[2] *Ibid*.
[3] International Bioethics Committee, *Report of the IBC on updating its reflection on the human genome and human rights*, UNESCO 2015, p. 27.
[4] *Ibid*.
[5] De Paor A., Blanck P., *Precision Medicine and Advancing Genetic Technologies-Disability and Human Rights Perspectives*, "Laws" 5:36 (2016), p. 7.

medical and technological developments, there is a broad range of different perspectives within the disability community: while some argue in support of the importance of treatments, thus viewing genetic interventions favourably, others prioritize the removal of social barriers as the more urgent concern.[6]

This contrast mirrors two of the three main models that are generally referred to, within the bioethical debate on disability: the medical model, the social model and the human rights model.[7]

The medical model of disability is based on the losses or disadvantages implied in the life of an individual with disabilities, thus entailing that this 'divergence' from the 'norm' requires cure and remedies to modify the person with the aim of better adapting them to the environment in which they live, in the attempt to enable them to live a 'normal' life.[8] This model may be seen as offering an argument in favour of gene editing, which can be considered as a means of improving people's lives, through the 'alleviation' of their disabling conditions.[9] More broadly, it could be argued that the idea of a life without certain genetic conditions is 'preferable' is grounded, although implicitly, in a medical model of disability.

From this perspective, many activists interpret genetics as another means of inflicting injustices on people with impairments, through the definition of disability in medical terms and the submission of people with genetic conditions to reproductive controls and medical interventions.[10] For this reason, most disability activists are averse to genetic approaches to disability, arguing that they are inherently discriminatory, that they imply a negative judgement towards disabled lives or will result in a harsher discrimination against disabled people.[11]

On the other hand, at the core of the social model of disability is the concept of 'systemic disadvantage', which emphasises the structural and social obstacles

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[6] De Paor A., Blanck P., *Precision Medicine and Advancing Genetic Technologies-Disability and Human Rights Perspectives*, "Laws" 5:36 (2016), p. 7.
[7] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 6.
[8] *Ibid*.
[9] De Paor A., Blanck P., *Precision Medicine and Advancing Genetic Technologies-Disability and Human Rights Perspectives*, "Laws" 5:36 (2016), p. 7.
[10] Shakespeare T., *Disability, Genetics and Global Justice*, "Social Policy and Society" 4:1 (2005), p. 87.
[11] *Ivi*, p. 88.

raised – whether consciously or unintentionally – by society; hence, disability is considered as a social construct rooted in discrimination, that reduces personhood to the individual's condition.[12] Moreover, a key characteristic of this model is the distinction between the *impairment* a person may have and the *disability* they could experience[13] related to society within a systemic perspective: according to this paradigm, any physical or psychological alteration does not automatically constitute a disability, unless society fails to integrate people with such differences; in other terms, disability is seen as a condition that is, in some way, inflicted to these individuals hindering their full inclusion within the context in which they live.[14] Consequently, this perspective suggests that the employment of technologies such as gene editing is inadequate because what should be worked on is the social environment we live in, not the genetic predispositions of the future persons.

As Tom Shakespeare – a social scientist and bioethicist – illustrates, the social model "has been called 'the big idea' of the disability movement"[15], since to many it represents the core political principle that not only initially sparked, but also keeps on supporting the disability rights movement.[16]

Another important model is the human rights one, that offers a combination between the backbone of the social model and minor factors of the medical one; it is based on the concept of human dignity as a moral value granted to each person because of their humanity, regardless of any social status, gender or any other trait.[17] A full definition of 'human dignity' is beyond the scope of this thesis, but four requirements can be identified to ensure that a person is treated with dignity: (I) the respect to the person's physical integrity, (II) the inherent right to be recognized as an individual with a personality, (III) the possibility of having a say

[12] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 7.
[13] Coleman-Fountain, E., McLaughlin, J. *The interactions of disability and impairment*, "Social Theory & Health" 11:2 (2013), p. 134.
[14] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), pp. 7-8.
[15] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 11.
[16] *Ibid*.
[17] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 8.

in decisions affecting their lives and of making their own decisions, (IV) the access to a fair portion of society's resources.[18]

More generally, the use of this concept is important because it entails that a person's medical characteristics should be taken into account only when strictly necessary, since from this perspective the 'problem' is external to the individual; within this framework, a view supporting of genetic interventions is considered retrograde as it reflects a medical standpoint, according to which individuals affected by disabilities are considered as 'inferior' and necessitate improvement.[19]

From the human rights standpoint, the core criticism regarding genomic technologies is that their future pervasive accessibility and use could, in the long run, threaten and denigrate people with disabilities, unless appropriate rights safeguards are introduced.[20]

4.2 Tom Shakespeare: the Need for a Multifactorial Approach

Taking a step back to the medical and the social model, over the years, the dichotomy between these two models has become more rigid: in Britain, but also increasingly internationally, the term 'social model' has been associated with a progressivist attitude towards disability, whereas the 'medical model' is considered to represent a backward-looking and retrograde approach.[21]

The impact of the spread of the social model has been indeed immense, particularly on disabled people themselves: while, according to the traditional medical model of disability, the cause of disabled people's problems is identified in their bodies, the social model blames those difficulties on social oppression and exclusion.[22] This shift in determining the source of these problems was, and continues to be,

[18] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), pp. 8-9.
[19] De Paor A., Blanck P., *Precision Medicine and Advancing Genetic Technologies-Disability and Human Rights Perspectives*, "Laws" 5:36 (2016), pp. 7-8.
[20] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 9.
[21] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 11.
[22] Shakespeare T., Watson N., *The social model of disability: an outdated ideology?*, "Research in Social Science and Disability" 2 (2002), p. 5.

profoundly liberating for disabled persons, because the shift in the cause of those troubles implies a shift in where responsibility lies: it is society that must change.[23] In fact, the key strength of the disability model is its simplicity, which is effectively captured in the slogan "disabled by society, not by our bodies".[24] However, as Shakespeare and Watson observe, the exact success of this model now constitutes its main flaw: it has come to be considered as a dogma that cannot be questioned, and it tends to reduce the complexity of reality to rigid dichotomies, such as the one of the disabled person as oppressed versus the society as the oppressor.[25]

Moreover, Shakespeare and Watson argue that the social model neglects the reality of impairments, of which there are many different kinds: they can be congenital or acquired, static or episodic, and they concern the look or the functions of the body.[26] The social model of disability overlooks all of these nuances, yet they are highly significant both at the individual and social level.[27]

Another aspect that Shakespeare and Watson find questionable is that the social model advocates establish a sharp distinction between impairment and disability.[28] According to this perspective, the *impairment* is defined as a biologically determined trait that the individual cannot simply change[29] and that entails a deficit or abnormality – understood as a serious deviation from established statistical norms – in physical structure or physiological functions.[30] Hence, while impairment is related to a disorder in bodily functioning, d*isability* is outlined as a condition in which a person's ability to fully experience community life is reduced,

[23] Shakespeare T., Watson N., *The social model of disability: an outdated ideology?*, "Research in Social Science and Disability" 2 (2002), p. 5.
[24] Shakespeare T., Watson N., *The social model of disability: an outdated ideology?*, "Research in Social Science and Disability" 2 (2002), p. 6.
[25] *Ibid*.
[26] *Ivi*, p. 12.
[27] *Ibid*.
[28] *Ivi*, p. 15.
[29] Wasserman D., Blustein J., Putnam D., *Disability: Definitions, Models, Experience*, in Zalta E.N. (ed.), *The Stanford Encyclopedia of Philosophy*, 2020.
[30] World Health Organization, *International classification of functioning, disability and health (ICF)*, Geneva: World Health Organization, 2001, p. 190.

compared to that of other members of society, as a result of physical or social obstacles.[31]

The problem with this polarization, according to Shakespeare and Watson, is that the biological differences that we label as impairments do not exist in neutral, non-social frameworks: the very terms we use to describe impairments are shaped by our socio-cultural context[32] and impairment is always, inevitably experienced within the social environment.[33] The two authors, consequently, claim that the inadequacy of the distinction between impairment and disability becomes evident when the question is asked: "where does impairment end and disability start?".[34]

As Shakespeare observes, it is undeniable that environmental, social and economic policies affect the condition of people living with disabilities;[35] however,

> Disabled people face both discrimination and intrinsic limitations. […] Even if social barriers are removed as far as practically possible, it will remain disadvantageous to have many forms of impairment.
>
> […] While acknowledging the benefits of the social model in launching the disability movement […] it is my belief that the social model has now become a barrier to further progress.
>
> As a researcher, I find the social model unhelpful in understanding the complex interplay of individual and environmental factors in the lives of disabled people. […] it seems to me that the social model is a blunt instrument for explaining and combating the social exclusion that disabled people face, and the complexity of our needs. […] A social approach to disability is indispensable. The medicalization of disability is inappropriate and an obstacle to effective analysis and policy. But the social model is only one of the available options for theorizing disability. More sophisticated and complex approaches are needed […].[36]

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[31] Anastasiou D., Kauffman J.M., *The Social Model of Disability: Dichotomy between Impairment and Disability*, "Journal of Medicine and Philosophy" 38 (2013), p. 442.
[32] Shakespeare T., Watson N., *The social model of disability: an outdated ideology?*, "Research in Social Science and Disability" 2 (2002), p. 16.
[33] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 23.
[34] Shakespeare T., Watson N., *The social model of disability: an outdated ideology?*, "Research in Social Science and Disability" 2 (2002), p. 17.
[35] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 11.
[36] Shakespeare T., *The Social Model of Disability*, in L.J. David (ed.), *The Disability Studies Reader*, Routledge, New York 2013., p. 220.

For this reason, Shakespeare proposes an alternative model, stepping outside the 'medical *versus* social' dichotomy and encouraging a multifactorial approach:

> I want to sketch how an alternative social approach to disability might reconcile different factors, avoid the perils of either biological or social or cultural determinism, and serve as the basis for a progressive politics.[37]

This approach of 'critical realism' is influenced by elements of feminism, such as the concept of "the personal being political"[38] and the ethics of care, but also by the Aristotelian virtue ethics and Sen and Nussbaum's capabilities approach.[39] Shakespeare finds it functional because it allows for complexity,[40] an element whose lack constitutes the main criticism directed at the social model; [41] he indeed provides a very clear description of this alternative model:

> Critical realism means acceptance of an external reality: […] the independent existence of bodies which sometimes hurt, regardless of what we may think or say about those bodies.[42]

In fact, critical realists draw a distinction between ontology, that deals with what exists, and epistemology, that concerns our understanding of what exists: labels identify disease, rather than constituting it, so any opinion or perspective towards disability cannot deny the fact that impairment itself existed and has its own empirical reality.[43] As Danermark and Gellerstedt state,

> This implies that injustices to disabled people can be understood neither as generated by solely cultural mechanisms (cultural reductionism) nor by socio-economic mechanisms (economic reductionism) nor by biological mechanisms (biological reductionism). In sum, only by taking different levels, mechanisms and contexts into account, can disability as a phenomenon be analytically approached.[44]

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[37] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 72.
[38] *Ibid*.
[39] *Ibid*.
[40] *Ivi*, p. 73.
[41] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 8.
[42] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 73.
[43] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 73.
[44] Danermark B., Gellerstedt L.C., *Social justice: redistribution and recognition- a non-reductionist perspective on disability*, "Disability & Society" 19:4 (2004), p. 350.

The method that Shakespeare wants to adopt stresses precisely the fact that disability is always an interaction between individual and structural factors, which consequently calls for a holistic approach: the way a disabled person experiences life is influenced by the interaction between both individual and external factors, dependent on the context they live in.[45] Shakespeare does not understand disability merely in terms of external disabling barriers, since he argues that the difficulties associated with disability would not be fully removed by any possible social arrangement:[46] even in a highly accessible world, there will always remain some form of disadvantage implied in many impairments.[47]

Claiming that people are disabled by society rather than their bodies – an argument frequently used to label gene editing as illegitimate, since it would not solve the 'real' problem, that is society's disposition – has surely been valuable in drawing attention to impediments made by humans to social participation, but it is an incomplete perspective: people with impairments will unavoidably experience disadvantage because of their bodies, for example people with visual impairments cannot observe a sunset and people who use a wheelchair may not be able to visit beaches or mountains.[48] Some people's impairments cause pain and debility that could maybe be alleviated by barrier-free environments, but not eliminated.[49] That is why, according to Shakespeare, the barrier-removal 'solution' to disability is not sufficient, thus undermining the core assumptions of the social model: the uniqueness of impairment produces disadvantages that cannot be eased by any inclusive social system, so the eradication of barriers cannot be an end in itself but a means to an end, always with the ultimate goal of improving the quality of life of people with impairments.[50]

[45] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 75.
[46] *Ibid*.
[47] *Ivi*, p. 42.
[48] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 36.
[49] *Ivi*, p. 40.
[50] *Ivi*, p. 41.

Shakespeare defines his approach as 'non-reductionist', because he considers limitations as a combination of impairment with certain contexts;[51] in fact, he criticizes what he sees as a widespread reluctance to acknowledge the importance of the body[52] and he underlines the need for a progressive disability politics to deal with impairment, not to dismiss it.[53]

A common claim among disability rights activists, in fact, is that disability is not inherently negative, since it constitutes a natural dimension of human diversity that should be valued, rather than deplored and 'cured'.[54]

Shakespeare, however, claims that preventing people from becoming impaired is just as important, globally, as preventing people becoming disabled, noting that the removal of barriers alongside a policy of inclusion and respect could still be the best way to deal with those who are already affected by impairments, or whose infirmities are not simply treatable.[55] Instead, for the large part of population at risk of impairments, he considers the possibility of preventing impairment to be crucial, arguing – in contrast to the majority of disabled activists, that regard impairment as a nuance of human diversity – that infirmity should be prevented wherever possible, though not at any cost.[56]

Moreover, Shakespeare argues that actually many disabled people believe that, when it is possible, impairment should be prevented or treated, which is evidenced by the fact that especially the individuals living with degenerative conditions are usually in favour of biomedical progresses, such as gene therapy or stem cell research. [57] Shakespeare also outlines the three macro-arguments that are generally presented to demonstrate that genetics is incompatible with social justice; the first reason is that access to genetic services may be characterized by disparities, as well as insufficient fundings for them.[58] The second one is that focusing on the

[51] *Ivi*, p. 75.
[52] Shakespeare T., *Disability, Genetics and Global Justice*, "Social Policy and Society" 4:1 (2005), p. 88.
[53] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 75.
[54] Barnes E., *Valuing Disability, Causing Disability*, "Ethics" 125:1 (2014), p. 88.
[55] Shakespeare T., *Disability, Genetics and Global Justice*, "Social Policy and Society" 4:1 (2005), p. 89.
[56] Shakespeare T., *Disability, Genetics and Global Justice*, "Social Policy and Society" 4:1 (2005), p. 90.
[57] *Ibid*.
[58] *Ivi*, p. 91.

prevention of impairment, rather than disability, is inadequate; the third is that an excessive focus on genetics and biomedicine may take attention away from the need to provide basic healthcare to all.[59] He then comes to the conclusion that each of these argumentations occur because of the context in which genetic services are provided, not because genetics is inherently bad.[60]

4.3 Slippery slope and the risk of eugenic drifts

Slippery slope

'Slippery slope' arguments are frequently invoked in debates concerning biomedical ethics[61]– including the one on reproductive gene editing – to argue against unintended and potentially critical consequences arising from the original technique.[62] In many cases the initial aim is generally considered morally legitimate, which cannot be yet said of subsequent developments that diverge from it.[63]

Generally, the argument can be outlined as follows: a criterion or technology, or method X is applied to a given situation or problem A and this initial application is morally acceptable, in some cases even laudable.[64] Then, the scope of X is gradually extended to a new area B, then to C and finally to D, which is morally unacceptable; in order to avoid this, it is argued that the original application of X to A should be refused.[65] The slippery slope argument rests on two general assumptions: (I) the slope is in fact 'slippery' in the sense that, once the application of X to A is allowed, it becomes impossible to stop he progression toward the final

[59] *Ibid*.
[60] *Ibid*.
[61] Walton D., *The Slippery Slope Argument in the Ethical Debate on Genetic Engineering of Humans*, "Sci Eng Ethics" 23 (2017), p. 1510.
[62] *Ibid*.
[63] Kropf M., *The ethically significant difference between dual use and slippery slope arguments, in relation to CRISPR-Cas9: philosophical considerations and ethical challenges*, "Research Ethics" 21:2 (2025), p. 347.
[64] de Beaufort I., Hermeren G., *The slippery slope, some remarks on the long and winding road to heaven or hell*, "Ethics, Medicine and Public Health" 3 (2017), p. 422.
[65] *Ibid*.

stage D; (II) D is not just wrong but often catastrophic, absolutely morally unacceptable and therefore it must be avoided by all means.[66]

In the case of germline gene editing, the slippery slope argument is one of the most used argumentative strategies and, according to it, accepting germline genome editing treatments could spark an out of control sequence towards threatening and unintended outcomes, such as an eugenics shift or the normalization of enhancement practices; therefore, to ward off such scenarios, any germline gene editing intervention should be prohibited.[67]

It can be helpful to observe that a distinction is commonly drawn between a logical version of this argument and an empirical/psychological one: on one hand, the logical form revolves around the logical strength of the argument, according to which once the initial step has been taken one is logically committed to all the following steps, thus 'sliding' to the bottom of the slope unless there is a sufficiently strong justification not to take one or more of the later steps.[68]

On the other hand, the empirical/psychological version of the argument focuses on the prediction that, due to psychological reasons, the acceptance of a certain practice will result in the acceptance of other ones, because individuals will be prone to approve of similar practices, being unable to identify any significant distinction between them; the emphasis is thus on the predictions about what is likely to occur.[69] According to this variant, then, the acceptance of GGE could gradually numb society's sensitiveness about genetic enhancement, ultimately culminating in a new form of coercive eugenics.[70] Such concerns are not surprising, given that other biomedical practices such as prenatal screening and

[66] *Ibid.*
[67] Battisti D., *Genome editing: slipping down toward Eugenics?*, "Medicina Historica" 3:3 (2019), p. 206.
[68] Baylis F., *Altered Inheritance. CRISPR and the Ethics of Human Genome Editing*, Harvard University Press, Cambridge 2019, p. 176.
[69] *Ibid.*
[70] Battisti D., *Genome editing: slipping down toward Eugenics?*, "Medicina Historica" 3:3 (2019), p. 206.

testing and preimplantation genetic diagnosis have already been associated with eugenic worries.[71]

Eugenics

To better understand why this juxtaposition is often made, it can be helpful to briefly mention to the history of eugenics. In the late 19th century, following the diffusion of Darwinian evolutionary theory, a number of alarming proposals emerged, among which this one;[72] the term 'eugenics' was coined by Francis Galton by combining the Greek prefix *eu-*, meaning 'well' or 'good', with the suffix *-genes*, meaning 'born', and in his 1883 book "Inquiries into Human Faculty and Its Development" Galton presented eugenics as[73]

> the science of improving stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognizance of all influences that tend in however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable.[74]

The entire eugenics movement rested on ideological assumptions (racism, classism, nationalism) and scientific errors: nowadays we know the belief that only individuals with certain physical traits can acquire particular intellectual capacities lacks any scientific basis.[75]

Galton then presented two measures with the intent of safeguarding the 'fit' traits of the human species: on one side positive eugenics, which encouraged reproduction among individuals with qualities above the norm; on the other, negative eugenics in order to limit the reproduction of 'unfit' individuals through sterilization, abortion and contraceptive methods.[76] Originally, Galton intended these measures as a matter of individual choice, but following the global spread of

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[71] Wiley L., Cheek M., LaFar E., et al., The Ethics of Human Embryo Editing via CRISPR-Cas9 Technology: A systematic Review of Ethical Arguments, Reasons, and Concerns, "HEC Forum" 37:2 (2025), p. 277.
[72] Battisti D., *Genome editing: slipping down toward Eugenics?*, "Medicina Historica" 3:3 (2019), p. 207.
[73] Agar N., *Why We Should Defend Gene Editing as Eugenics*, "Cambridge Quarterly of Healthcare Ethics" 28:1 (2019), p. 9.
[74] Galton F., *Inquiries into Human Faculty and its Development*, Macmillan, London 1883, p. 17.
[75] Battisti D., *Genome editing: slipping down toward Eugenics?*, "Medicina Historica" 3:3 (2019), pp. 208-209.
[76] Battisti D., *Genome editing: slipping down toward Eugenics?*, "Medicina Historica" 3:3 (2019), p. 208.

his ideas the eugenics movement gained considerable attention from various national governments which began promoting eugenics policies, until they culminated in the tragic history of Nazi Germany,[77] which professed to eliminate the 'less suitable' bloodlines:[78] historians estimate that between 200.000 and 250.000 individuals with physical and intellectual disabilities were killed under the Aktion t4 Program, between 1939 and 1945.[79] And it has been extensively documented that Nazi Germany was not the only government invoking eugenics to motivate morally deplorable practices.[80]

It is not surprising, then, that disability rights advocates are concerned about a potential return of eugenics, since the target of such policies were almost always groups with physical or mental disabilities.[81]

'Eugenics' is therefore considered a 'dirty' word and in this regard any association of genetics with eugenics is highly defamatory; this kind of objection, often referred to as 'the eugenics argument', as already mentioned is neither recent nor limited to the CRISPR debate, in fact it is often mentioned in different bioethical discussion concerning reprogenetics, in particular about prenatal testing and pre-implantation genetic diagnosis.[82] This critique, however, seems to deepen in light of the potential impact of germline gene editing, since with techniques like CRISPR it is possible to directly target a genetic change that would have otherwise been transmitted to future generations.[83] As Gebelhoff stresses, "we're no longer in an era where scientists can shrug off eugenicist rhetoric as too distant to worry about": Britain already approved public funding for human genome editing projects and in light of the rapid progresses of CRISPR technology it is probable

[77] *Ibid*.
[78] Agar N., *Why We Should Defend Gene Editing as Eugenics*, "Cambridge Quarterly of Healthcare Ethics" 28:1 (2019), p. 9.
[79] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 3.
[80] Agar N., *Why We Should Defend Gene Editing as Eugenics*, "Cambridge Quarterly of Healthcare Ethics" 28:1 (2019), p. 9.
[81] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 3.
[82] Ranish R., '*Eugenics is Back?' Historic References in Current Discussions of Germline Gene Editing*, "Nanoethics" 13 (2019), pp. 210-211.
[83] *Ivi*, p. 211.

that other governments will adopt similar approaches;[84] for this reason, there is a growing concern that a neo-eugenics movement may focus on the selection of specific genes, while erasing the genes that cause disability.[85]

One of the most mentioned concerns regarding the risk of a eugenic drift arising from the application of gene altering interventions for reproductive purposes is, in fact, related to the potentially adverse consequences such technologies may have on individuals living with disabilities.

The bioethicist Rosemarie Garland-Thomson, for instance, defines as rooted in an 'eugenic logic' the belief that the world would be a better place if disability could be eliminated[86] and she considers the use of gene altering technologies the equivalent of what she calls 'velvet eugenics', that is the propaganda of the standardization of human variation in the name of individual, market-driven freedom,[87] claiming that they implement a policy that prevents people with disabilities from being born.[88] She explicitly declares that "much current reproductive technology, including gene editing, carries out a new eugenics in the name of health and reproductive liberty".[89]

4.4 rGE, Slippery Slope, Eugenics: Concluding Remarks

However, the plausibility that the employment of gene editing could boost negative attitudes against people with disabilities depends on specific social conditions and whether discriminatory attitudes actually arise remains an open issue, that can be analysed through empirical research; for example, the Genetic Alliance UK showed that the largest part of patients with rare or genetic conditions support the use of gene editing to correct a defective gene in an embryo or foetus and, although

[84] Gebelhoff R., *What's the difference between genetic engineering and eugenics?*, "The Washington Post", 22nd February 2016.
[85] Conti A., *Drawing the line: Disability, Genetic Intervention and Bioethics*, "Laws" 6:9 (2017), p. 3.
[86] Garland-Thomson R., *The Case for Conserving Disability*, "Bioethical Inquiry" 9 (2012), pp. 339-340.
[87] Garland-Thomson R., *How We Got to CRISPR: The Dilemma of Being Human*, "Perspectives in Biology and Medicine" 63:1 (2020), p. 34.
[88] Sufian S., Garland-Thomson R., *The Dark Side of CRISPR*, "Scientific American", 16th February 2021.
[89] Garland-Thomson R., *How We Got to CRISPR: The Dilemma of Being Human*, "Perspectives in Biology and Medicine" 63:1 (2020), p. 34.

this study will not resolve the conflict over whether new technologies may induce discriminatory tendencies, it does question the assumption that gene editing necessarily results in negative approaches against people with disabilities.[90]

Moreover, unlike other techniques such as pre-conception or prenatal genetic screening, GGE adopts a fundamentally different approach to genetic disease prevention: it focuses on correcting or removing disability genetic traits, instead of the so-called 'seek and destroy' method of currently used technologies (such as preimplantation genetic diagnosis): by preserving the life of the embryo while eliminating its disabling trait, germline gene edit is able to avoid one of the most significant social and ethical criticism towards other approaches to genetic disease prevention, that is the consideration of disability as more important than the life itself of the embryo.[91] Therefore, gene editing does not convey the idea that not living at all is better than a life with a certain condition and it does not lead to the disposal of embryos, since it intervenes on the manifestation of those possible traits, thus preventing them; from this follows a completely diverse message, namely that living without the condition is better than living with it, an outcome that – according to GGE supporters – sounds plausible to everyone.[92]

The conclusion Iñigo de Miguel Beriain draws from this is that germline gene editing appears to be not only legitimate, but also a required intervention to deal with disabling genetic conditions found in in vitro embryos.[93] Clearly, this opinion is not shared by everyone, for instance Felicity Boardman presents two of the main arguments against gene editing technologies from a disability standpoint: first, the need to acknowledge that not every condition leads to a poor life, so at least some of them should not be eliminated; secondly, she emphasizes the importance of the so-called 'expressivist objection.[94]

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[90] Ranish R., '*Eugenics is Back?' Historic References in Current Discussions of Germline Gene Editing*, "Nanoethics" 13 (2019), p. 214.

[91] Boardman F., *Human genome editing and the identity politics of genetic disability*, "Journal of Community Genetics" 11 (2020), p. 125.

[92] de Miguel Beriain I., *Gene editing and disabled people: a response to Felicity Boardman*, "Journal of Community Genetics" 11 (2020), p. 241.

[93] *Ibid*.

[94] *Ibid*.

More specifically, regarding the first issue Boardman states that most people living with genetic disabilities maintain that a reduction in the number of people born with their condition would represent a loss for society.[95] de Miguel Beriain questions this line of reasoning: he does not think Boardman's considerations are effective in demonstrating how living with a disability may be equivalent to, if not better than living without it.[96] However, he assumes that some patients, which he labels as A-type patients, could be adverse to genetic therapy; the problem is how to establish to what extent A-type patients reflect the sentiment of the general population.[97]

de Miguel Beriain draws attention to the difficulty of drawing unequivocal conclusions, particularly because the only patients able to actually compare the experience of living with and without disease are those who did not suffer from their condition since childhood, but many genetic disorders manifest very early in life.[98] This thesis of his appears to be validated by the fact that also Boardman herself acknowledges that the attitudes of adults with genetic disabilities on screening and testing are sometimes contradictory, suggesting that some patients may potentially be supportive of GGE.[99] de Miguel Beriain refers to this kind of patients as B-type patients, which may think that the eradication of distress due to a specific condition could allow them to experience better lives; this raises a crucial question: how can it be established whether an embryo with a definite condition will grow into an A-type or B-type patient?[100]

He argues that no certain answers can be given, but he outlines two possible scenarios: the potential patient is grateful that gene editing has not been employed, as they appreciate living with that condition, or, in contrast, they may have

[95] Boardman F., *Human genome editing and the identity politics of genetic disability*, "Journal of Community Genetics" 11 (2020), p. 125.
[96] de Miguel Beriain I., *Gene editing and disabled people: a response to Felicity Boardman*, "Journal of Community Genetics" 11 (2020), p. 241.
[97] *Ibid*.
[98] *Ivi*, pp. 241-242.
[99] de Miguel Beriain I., *Gene editing and disabled people: a response to Felicity Boardman*, "Journal of Community Genetics" 11 (2020), p. 242.
[100] *Ibid*.

preferred not to suffer from that condition; what he points out, however, is that it is probable that if through gene editing the individual does not develop a specific condition they will not be deprived of anything.[101] de Miguel Beriain concludes from this that we are looking at a prospect in which three out of four possible outcomes support the morality of gene editing interventions, when weighed in light of the embryo's interests.[102]

Boardman's second argument is one of the most frequently raised critiques from the disability rights perspective to reprogenetic practices, referred to as the 'expressivist objection'[103] (which, more precisely, includes a set of objections since there are several versions of it), whereby the attempt to develop interventions designed to correct, alleviate or prevent genetic conditions expresses – and, consequently, presupposes – a negative and dangerous evaluation of disabled individuals.[104] As a result, according to many it would be wrongful to edit only certain pathological conditions in embryos, due to the fact that it could further disfavour those who are currently living with those conditions; it is an objection that is very frequently raised, in fact several studies use it as an argument against the employment of GGE.[105]

de Miguel Beriain maintains that the interest and well-being of the patients should be the sole principle taken into account for medical decisions, so if the prevention of a condition serves that patient's interests, they should not be overruled by broader societal considerations.[106] This, of course, does not mean that discrimination against disabled people is justified, but that it is right to oppose to pain through all available means and to deliberately bring into the world additional disabled people cannot be considered a way to address the already existing

[101] *Ibid*.
[102] *Ibid*.
[103] Boardman F., *Human genome editing and the identity politics of genetic disability*, "Journal of Community Genetics" 11 (2020), p. 125.
[104] Buchanan A., *Choosing who will be disabled: genetic intervention and the morality of inclusion*, "Social philosophy & policy" 13:2 (1996), p. 29.
[105] de Miguel Beriain I., *Gene editing and disabled people: a response to Felicity Boardman*, "Journal of Community Genetics" 11 (2020), p. 242.
[106] *Ibid*.

suffering: it would mean treating human beings as means, thus violating human dignity.[107]

According to Buchanan, even if the expressivist objection were accepted, its scopes would be restricted to certain interventions aimed at preventing disability, specifically those that imply the avoidance of the conception of embryos that would be affected by disabilities, or the termination of pregnancies of this kind; he then argues that other applications of genetic science to reduce the incidence of disability, such as gene alterations, would remain legitimate.[108]

Buchanan considers as 'evident' that the elimination, inactivation or alleviation of a disabling genetic defect via gene surgery on embryos or gametes by no means presupposes the idea that only perfect individuals should exist, nor that the lives of disabled individuals are not worth living, "anymore than performing conventional surgery to restore a blind person's sight does".[109] In both cases, indeed, the subtended reason for intervention is the mere desire to eliminate possible significant constraints on the subject's opportunities and this purpose could rationally drive one's decisions without necessarily entailing the belief that a life lived with such limitations is not worth living.[110]

Also Shakespeare claims there is no inconsistency in supporting the rights of people with disabilities while, at the same time, preventing more people from becoming impaired and that

> Because impairment is not a neutral state, but a condition that is generally unwelcome and best avoided, attempts to reduce the numbers of disabled children being born are acceptable, if they are promoted in ways that do not threaten existing disabled children and adults.[111]

Another line of argument frequently brought up by disability activists is that living with certain disabilities for some individuals results in the development of qualities

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[107] *Ibid*.
[108] Buchanan A., *Choosing who will be disabled: genetic intervention and the morality of inclusion*, "Social philosophy & policy" 13:2 (1996), p. 30.
[109] *Ivi*, pp. 30-31.
[110] *Ivi*, p. 31.
[111] Shakespeare T., *Disability Rights and Wrongs Revisited* (2nd ed.), Routledge, London 2013, p. 120.

that they might not have had if they had not suffered from those impairments and, while this can be acknowledged, arguments of this kind are often not totally successful: various bad things can serve a good purpose, yet they do not cease to be bad.[112] Let's examine some cases of people who, after becoming quadriplegic or paraplegic because of accidents, reach remarkable accomplishments: not only they often exhibit special characteristics, but they also inspire others; however, does this entail that we should stop trying to prevent serious accidents?[113] To assert such a thing seems implausible.

Buchanan highlights another common objection raised by disability scholars, that is what he calls the 'loss of support' argument: according to it, the reduction of the number of individuals with a particular disability would result in a decreased support for those who have it.[114] Buchanan first of all points out that data should be provided to support this claim and, moreover, that reducing the incidence of a genetic disease could potentially allow for more resources to be directed toward the support of fewer people already living with that disease.[115]

Additionally, the idea that support will decrease as the recurrence of genetic diseases reduces is everyday less likely, precisely because advocates for disability rights have achieved important victories in raising awareness about the need for support; lastly, even if some loss of support were to actually occur, it would not automatically mean that trying to prevent the incidence of disabilities is wrong, since one of the problems of the 'loss of support' argument is that it only focuses on the interest of those already affected by disabilities, but what about the interests of those who wish to avoid them?[116]

Buchanan even argues that it is likely that situations in which justice not only allows, but requires interventions to correct or prevent genetic flaws;[117]

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[112] Coady C.A.J., *Playing God*, in Savulescu J., Bostrom N. (eds.), *Human Enhancement*, Oxford University Press, Oxford 2009, pp. 171-172.
[113] *Ivi*, p. 172.
[114] Buchanan A., *Choosing who will be disabled: genetic intervention and the morality of inclusion*, "Social philosophy & policy" 13:2 (1996), p. 22.
[115] *Ibid*.
[116] *Ibid*.
[117] *Ivi*, p. 24.

> The basis of this conclusion is the assumption that an adequate account of justice will include a place for a commitment to equal opportunity and that in some cases equal opportunity requires more than the removal of legal barriers to opportunity.[118]

In conclusion, genetics advocates – careful to distance themselves from the stigma that the old eugenics carries – underline that their primary goal is to alleviate all human from genetic diseases, with an underlying ideology of a progressive and universalistic ethic that has nothing with the old eugenics: the pursuit of progress through scientific innovations relies on an inclusive understanding of the value of human life, rather than a dangerous belief that only the supposed typical traits of a specific ethnicity, nation or social class are valuable.[119]

Moreover, the eugenics argument presupposes the inevitability of the 'slope', overlooking our faculty to make judicious assessments about different applications of the same technology[120] and a comparison with other reprogenetic technologies can effectively demonstrate that the 'slope' to the worst scenario is, in fact, not to be taken for granted: prenatal technologies, such as amniocentesis and PGD, have allowed for screening for embryonic of foetal diseases for more than fifty years, yet they have not resulted in problematic consequences as those pictured by proponents of the eugenics arguments.[121]

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[118] Buchanan A., *Choosing who will be disabled: genetic intervention and the morality of inclusion*, "Social philosophy & policy" 13:2 (1996), p. 24.
[119] *Ivi*, p. 19.
[120] Sheelan M., *Gene editing of human embryos and designing descendants*, "Maturitas" 94 (2016), p. 20.
[121] Ranish R., '*Eugenics is Back?' Historic References in Current Discussions of Germline Gene Editing*, "Nanoethics" 13 (2019), p. 213.

Conclusions

The purpose of this work is to reconstruct, in a broad outline, the debate on reproductive gene editing at least in some of its key points; as it has been seen, it is a layered and consistently evolving field, since the groundbreaking potential of genetic engineering offers unprecedented opportunities but, at the same time, implies considerable challenges.

Across these chapters, the discussion has aimed to demonstrate that, despite the risks and concerns outlined – and that it is crucial to take into account – the potential benefits of gene editing, once its application is proven to be safe, seem to outweigh the possible negative consequences and can thus justify a position in favour of such technologies, provided they are employed in solid regulatory frameworks.

The currently ongoing progress of science and biotechnologies indeed makes it essential to establish both an ethical and a regulatory framework to ensure that the application of reproductive gene editing is led by principles that respect human dignity and equity; for this reason, the major challenge lies in the effort of balancing out rGE's potential and the protection of core moral values.

The concerns outlined in the second chapter are significant, but not insuperable: as regards the safety issues, recent literature appears to show that the precision of tools such as CRISPR/9 is rapidly improving and, considering the remarkable progress it was made in recent years, it is plausible that the point at which these technologies will be considered totally efficient is not far off. As a recent study suggests, in fact, GE in embryos and germ cells may become technically feasible within the next generation, as a result of developments that substantially reduce off-target effect and enhance the outcome predictability.[1] As regard of future generations, moreover, it could be possible to develop consent frameworks that safeguard the rights of the future persons, while allowing the research to move forward.

[1] Visscher P.M., Gyngell C., Yengo L., Savulescu J., *Heritable polygenic editing: the next frontier in genomic medicine?*, "Nature" 637 (2025), pp. 637-645, doi: 10.1038/s41586-024-08300-4

Inmaculada de Melo-Martín's position was examined in the third chapter through a deep examination of some of her key works and, as already noted, her objections to genetic engineering – although grounded in legitimate concerns primarily about distributive justice – present notable theoretical limits and she seems to ignore the possibility of a strictly regulated therapeutic use of these technologies. Such a categorical rejection of gene editing, however, risks foreclosing the potentially beneficial developments, leaving future generations exposed to preventable suffering; additionally, de Melo-Martín fails to provide concrete alternative solutions, declining a technology that could contribute to alleviate suffering and improving the quality of life of those who will come after us.

The relationship between gene editing and disability, explored in the fourth chapter, constitutes the argumentative core of this thesis. Drawing on perspectives from disability studies and the disability rights critique, its aim was to challenge the common tendency to equate genetic interventions with 'eugenics'; in this regard it was presented a more nuanced or hybrid approach, such as Tom Shakespeare's, to emphasize a key point: when discussing disability, one is first and foremost speaking about embodied experiences of suffering. In this light, seeking to prevent the occurrence of certain pathologies through gene editing should not be understood as an attempt to discriminate people living with disabilities, but rather as an effort to offering future individuals a greater freedom of choice and possibly a better quality of life.

What emerges from this discussion is a pro-technology – while maintaining a cautious approach – standpoint for reproductive gene editing: if strictly oriented toward therapeutic aims and employed in a context of inclusive policies, rGE could even serve as a tool of social justice, rather than discrimination. It could be beneficial not only on an individual level but also on a collective one, resulting in lower long-term healthcare costs and overall better conditions for those who would have otherwise been born with severe genetic conditions.

In conclusion, the intent of this thesis was to argue that reproductive gene editing is not an apocalyptic threat, as it sometimes seems to be perceived: it is a powerful

tool, with substantial potential benefits, that we have a moral responsibility to govern wisely, rather than demonize. To fully dismiss the possibility of preventing genetic suffering, while we can, would mean to give up the ethical responsibility we hold toward future persons. By contrast, approaching it with caution, with a clear awareness of its associated risks, can turn it into a genuine step toward human progress; this does not mean that gene editing is a flawless tool – far from it – but rather that its challenges should not result in its outright rejection, as its potential positive impacts are too significant to be disregarded or overshadowed by its possible side effects.

It is therefore essential, as further shown by cases such as He Jiankui's, to avoid being caught unprepared with its arrival: since it cannot be excluded that the technique in question in a (probably not too distant) future will actually be made available to the public, the main issue about rGE may no longer be whether to authorize the employment of germline gene editing interventions, but rather how to guarantee that their application is controlled in a responsible way; in this respect, official institutions such as the National Academy of Sciences discuss this in terms of the need to establish a "responsible translational pathway" toward clinical use of rGE.[2]

The path ahead is surely long and demands dialogue and vigilance, but it shows how the bioethics of the future needs to be not only critical, but also constructive. Engaging all stakeholders and maintaining an ongoing dialogue between scientists and bioethicists is essential to develop clear and approved guidelines; a collaborative, interdisciplinary approach thus may be the key to fully benefit from this technology, while still preserving the values we consider the most important.

> Bioethics pushes scientists to acknowledge that they operate not within a vacuum but within a society in which diverse perspectives and values must be engaged. Bioethicists give voice to those divergent perspectives and provide a framework to facilitate informed and inclusive discussions that spur progress, rather than stall

[2] National Academy of Medicine, National Academy of Sciences, and the Royal Society, *Heritable Human Genome Editing*, Washington DC, The National Academies Press 2020, p. 121, doi: 10.17226/25665

it. In an era in which so many pressing challenges will depend on the innovations of science […] the need for progress that's both ethical and accountable has never been greater. [3]

[3] Neuhaus C.P., Caplan A.L., *Genome editing: Bioethics shows the way*, "PLOS Biology" 15:3 (2017), pp. 4-5.

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