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Ethical Discourse on Epigenetics and Genome Editing: The Risk of (Epi-) Genetic Determinism and Scientifically Controversial Basic Assumptions[1]

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1. Introduction

This chapter provides insight into the diverse ethical debates on genetics and epigenetics. Much controversy surrounds debates about intervening into the germline genome of human embryos, with catchwords such as *genome editing*, *designer baby*, and *CRISPR/Cas*.[2] The idea that it is possible to design a child according to one's personal preferences is, however, a quite distorted view of what is actually possible with new gene technologies and gene therapies. These are much more limited than the *editing* and *design* metaphors suggest. Such metaphors are therefore highly problematic phrases in the context of new gene technologies,

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[2] CRISPR: "Clustered Regularly Interspaced Short Palindromic Repeats"; Cas: "CRISPR associated enzymes." CRISPR/Cas is used in gene therapy to bind specifically to DNA and, in some cases, to modify it. This is a genetic engineering process that has its origins in forms of bacterial immune defence.

for two reasons. On one hand, to design a *child of choice* by modifying the genome would require modifying any gene of choice, which is more than can be done with current gene technologies, such as CRISPR/Cas. On the other hand, a modification of genes would need to be enough to create any characteristic of choice in the future child. The latter presupposes the assumption of *genetic determinism*.[3] Moreover, the CRISPR/Cas technology can not only be used in a potentially therapeutic manner at the germline level. In addition, there is the (more likely) scenario of a future clinical therapeutic use of these new gene technologies for modifying the DNA sequence of other cells of the body (somatic genome editing). There is also the option of modifying the epigenome, that is, the spatial configuration of DNA (epigenome editing) (see table 1).

Tab. 1. Genome Editing and Epigenome Editing.

	Genome editing	*Epigenome editing*
Method	Changing the DNA sequence (base sequence): • of germline cells, e.g., in embryos (germline intervention), • or of somatic cells (somatic genome editing).	Changing the structure of DNA for the purpose of influencing the transcription of DNA in the cell ("reading") and gene expression (conversion of DNA into proteins): • usually of somatic cells (somatic epigenome editing).
Application / Use cases	• Treatment of genetic diseases, • e.g., hemoglobinopathies (beta thalassemia, sickle cell disease …). What are hemoglobinopathies? • Disturbance of the formation or function of the red blood pigment hemoglobin with sometimes severe symptoms.	• Treatment of epigenetic diseases, • e.g., imprinting disorders (Prader-Willi syndrome, Angelman syndrome, …). What are imprinting disorders? • Syndromes caused by incorrect "reading" of genes with a combination of neurological symptoms, growth and metabolic impairments.

[3] The different terms (here also *-isms*) are explained in the following text; for an overview see also table 2.

Scientific background:

- Gemome and epigenome editing are gene technological methods.
- As in genome editing, the “CRISPR/Cas complex” is frequently used in epigenome editing, other available "tools" are Zinc Finger Nucleases (ZFN) and “Transcription Activator-Like Effector Nucleases” (TALENs).
- However, the Cas enzyme, which is generally used in genome editing to induce DNA breakage, is modified in such a way that it is provided in the form of “catalytically deactivated-Cas” (dCas).
- The use of “CRISPR/dCas” in epigenome editing thus enables binding to DNA without causing DNA breakage.
- While genome editing changes the DNA sequence, epigenome editing aims to modify the epigenetic configuration of chromatin, e.g., DNA methylation change and histone acetylation change.

Like genetics and genome editing, epigenetics has been at the center of recent popular scientific[4] and ethical discourse[5] as well as scientific debates. The concept of epigenetics has given rise to very different notions of inheritability and responsibility for health,[6] which, however, are oftentimes based on scientifically controversial basic assumptions. That there continues to be *covert genetic determinism* in the form of *epigenetic determinism* (see table 2) in debates about epigenetics has been pointed out in ethical analyses of epigenetics.[7] Neither genetic determinism nor epigenetic determinism has been confirmed scientifically. It is therefore important to recognize the concepts that are discussed (and sometimes harshly criticized) in debates about genome editing and epigenetics—for example, concepts about the

4 The term “popular scientific discourse” covers texts that present scientific topics in a form understandable by the general public—for example, media science texts or self-help books (in German, “Ratgeberliteratur”) on health topics.

5 Of course, ethics is also to be counted among the disciplines of humanities (and in German simply among the broader term “Wissenschaft,” often translated as “science,” albeit comprising sciences and humanities). In the present study, therefore, the use of the term “science” refers to natural science, unless otherwise stated.

6 On epigenetics, see the publication *Epigenetik. Implikationen für die Lebens- und Geisteswissenschaften*, by the Berlin-Brandenburg Academy of Sciences and Humanities, edited by Jörn Walter and Anja Hümpel (Baden-Baden: Nomos, 2017). That work provides an intensive analysis of the concept of heredity in the context of epigenetics, which is much more extensive and differentiated than can be done in the present chapter. For a more detailed discussion of this important topic, we therefore refer to Walter and Hümpel, *Epigenetik.* For the scientific basis of epigenetics, see also J. Walter and N. Gasparoni, “Themenbereich Epigenetik. Von Zellidentitäten bis hin zu Krankheiten und Therapien,” in *Fünfter Gentechnologiebericht. Sachstand und Perspektiven für Forschung und Anwendung*, ed. B. Fehse et al. (Baden-Baden: Nomos, 2021), 93–113; and A. Jawaid and I. Mansuy, “Generationsübergreifende Auswirkungen von Traumata. Implikationen für Individuen und Gesellschaft,” in Fehse et al., *Fünfter Gentechnologiebericht*, 277–98.

7 S. Schuol, “Widerlegt die Epigenetik den Gendeterminismus? Es kommt darauf an …,” in *Epigenetik. Ethische, rechtliche und soziale Aspekte*, ed. R. Heil et al. (Wiesbaden: Springer, 2016), 45–58; S. Schuol, *Das regulierte Gen. Implikationen der Epigenetik für Biophilosophie und Bioethik* (Freiburg/Munich: Karl Alber, 2017); and M. R. Waggoner and T. Uller, “Epigenetic Determinism in Science and Society,” *New Genetics and Society* 34, no. 2 (2015): 177–95, DOI: 10.1080/14636778.2015.1033052.

causal role of DNA for our own life course. This importance is based on the fact that if we understand such controversial concepts, we will be able to remain critical when evaluating scientific knowledge and ethical arguments about genome editing and epigenetics. This chapter, therefore, explains some of these concepts. For an ethical analysis of epigenetics as well as of genome editing, it is necessary to understand and critically reflect upon the underlying concepts of genetic determinism and other, related *-isms*. The following section offers a detailed introduction to these -isms (section 2; see also table 2).

Tab. 2. Analyzed Concepts.

	Definition	Section	Related areas of discourse			
			Scien.	P.-Scien.	Soc.	Eth.
Genetic essentialism	Idea that a person is determined solely, or at least to a predominant part, by their genes.	2.1			X	
Strong genetic determinism	Idea that a gene almost always determines a certain characteristic (a particular physical, behavioral, or character trait).	2.1			X	
Covert genetic determinism	Adoption of genetic determinism extended by the findings of epigenetics.	2.2	X	X	X	X
Epigenetic determinism	Combination of a) *Covert genetic determinism* and b) the scientifically not validated assumption of the possibility of a voluntary influencing of one's own epigenome and the epigenome of future generations and the responsibility derived from this.	2.2		X	X	X
Genetic (data) exceptionalism	Ethical-legal requirement that genetic data should be given an exceptionally high level of protection.	2.3			X	X
Epigenetic (data) exceptionalism	Ethical-legal requirement that epigenetic data should be given an exceptionally high level of protection.	2.3				X

Areas of discourse (abbreviations): Scien.= Scientific discourse; P.-Scien. = Popular science texts, e.g., guidebooks; Soc. = Societal discourse; Eth. = Ethical discourse. The occurrence of the individual *-isms* in the respective discourse areas is hypothetical, especially for societal discourse. Observations are based on assessments of the secondary literature on the respective concepts.

Section 3 provides an ethical analysis of genome editing and epigenetics based on the explanations in section 2. Section 3 focuses on inheritability and responsibility, justice, safety,

the problem of consent, and the effects of genome editing and epigenetics on embryos and future generations.

This section does not discuss in detail further points that can be found in ethical debates about epigenetics as well as in ethical debates about genome editing. These points include (among others):

- fear that the findings of epigenetics and that the methods of genome editing are misused—this also with respect to eugenics and *enhancement*;[8]
- naturalness—an issue we mention in passing a few times in the following analysis;
- a possible connection between the genome/epigenome and the concept of human dignity, and the derived danger of instrumentalization and infringement of autonomy when intervening in the genome or epigenome.

Since current discourse about ethical issues associated with genome editing focuses mainly on germline interventions, which are, for instance, interventions into a human embryo's genome, we mainly focus on germline interventions when comparing the debates on genome editing and on epigenetics in section 3.

2. -isms

An important concern of this chapter is to draw attention to the need for critical reflection on explicit, but far more often implicit, -isms within the discourse on epigenetics as well as genetics and genome editing. The following concepts or -isms, which are highlighted to varying degrees in scientific, popular scientific, societal, and ethical discourse, will be discussed—namely, genetic essentialism and strong genetic determinism (2.1), covert genetic

[8] See Dieter Birnbacher, "Gentechnisches Enhancement," in *Vierter Gentechnologiebericht. Bilanzierung einer Hochtechnologie* [Fourth Gene Technology Report], ed. F. Hucho et al. (Baden-Baden: Nomos, 2018), 237–50); see also below, section 3.1.

determinism and epigenetic determinism (2.2), genetic exceptionalism and epigenetic exceptionalism (2.3) (table 2).

We are aware that determinism, in particular, is a very strong term that suggests complete external determination.[9] We use this and the other -isms merely in reference to terms already introduced in ethical discourse, and do not wish to proclaim ourselves that humans are completely determined by their genes or epigenome.

In societal discourse, both ideas of genetic and epigenetic determinism are still present despite scientific findings that conflict with these concepts. Consequently, following an introduction to the various -isms, and in light of the new possibilities for intervening in both the genome and, in the future, perhaps also the epigenome of a human being, it may be asked: Can the procedures of genome and epigenome editing help to refute the assumption of genetic and epigenetic determinism or, on the contrary, do these new gene therapy procedures promote the notions of genetic and epigenetic determinism that are present in the current public discourse? This question is important for a critical reflection upon the -isms introduced here, and, thus, important for future research.

2.1. Genetic Essentialism and Strong Genetic Determinism

a) Concept

Genetic essentialism is based on the idea that the genotype completely determines the phenotype and the entire essence of a human being: "Genetic essentialism reduces the self to a molecular entity, equating human beings, in all their social, historical, and moral complexity,

[9] D. B. Resnik and D. B. Vorhaus, "Genetic Modification and Genetic Determinism," *Philosophy Ethics and Humanities in Medicine* 1, no. 9, online publication, Jun. 26, 2006, DOI: 10.1186/1747-5341-1-9.

with their genes."[10] This implies that the human being as such is solely, or at least to a significant degree, determined by its genes. This concept stands disproved by science.[11]

Furthermore, just as questionable as genetic essentialism—and necessary precondition of it—is the concept of strong genetic determinism. David Resnik and Daniel Vorhaus define strong genetic determinism as the assumption that "gene G almost always leads to the development of trait T. (G increases the probability of T and the probability of T, given G, is 95% or greater)."[12] Although now refuted by recent findings in human genetics, this "one-gene-one-trait" relation was held to be valid for a long time even within science.[13] Therefore, it can be assumed that the idea that there is a strong genetic determinism as well as a genetic determinism are still present within society.[14]

b) Critique

Both positions (strong genetic determinism and genetic essentialism) are harshly rejected within the philosophy and ethics of science.[15] This is based not only upon the fact that they are scientifically refuted, but also on the belief that genetic essentialism has implications that are ethically worrisome. Ilan Dar-Nimrod and Steven Heine point out that the idea that a person would be determined entirely through his or her genes might result in selective discrimination of persons with certain characteristics and of their relatives, a discrimination that might not take place if these certain characteristics had a nongenetic cause: "research has

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10 D. Nelkin and M. Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York: W. H. Freeman, 1995), 2.

11 B. Tappeser and A.-K. Hoffmann, "Das überholte Paradigma der Gentechnik. Zum zentralen Dogma der Molekularbiologie fünfzig Jahre nach der Entdeckung der DNA-Struktur," in *Der kritische Agrarbericht 2004*, ed. AgrarBündnis e.V. (Hamm: ABL Verlag, 2004), 220–24, https://www.kritischer-agrarbericht.de/fileadmin/Daten-KAB/KAB-2004/Tappeser_Hoffmann.pdf (accessed Febr 14, 2023); and Schuol, "Widerlegt die Epigenetik den Gendeterminismus?."

12 Resnik and Vorhaus, "Genetic Modification and Genetic Determinism" (*see supra* note 9).

13 Tappeser and Hoffmann, "Das überholte Paradigma der Gentechnik" (*see supra* note 11); and Schuol, "Widerlegt die Epigenetik den Gendeterminismus?" (*see supra* note 7).

14 Schuol, *Das regulierte Gen. Implikationen der Epigenetik für Biophilosophie und Bioethik* (*see supra* note 7).

15 I. Dar-Nimrod and S. J. Heine, "Genetic Essentialism: On the Deceptive Determinism of DNA," *Philosophical Bulletin* 137, no. 5 (2011): 800–18, DOI: 10.1037/a0021860.

shown that stronger genetic attributions for mental illness are associated with an increased desire for social distance from those with such illnesses . . . and their kin."[16]

While genetic causality is perceived negatively in these situations, the contrary might also be the case. If one assumes that genes are natural, that what is natural is morally *good* (*naturalistic fallacy*), and if one furthermore assumes that genetic essentialism is true, that is, that human beings are entirely determined through their genes, then all human traits, characteristics, and behaviors are believed to be morally good. There is no room for critique. Instead, because of the deterministic understanding, every human behavior is perceived as legitimate. Only the artificial modification of the human genome would offer some room for critique, since a genetically modified genome would no longer be perceived as natural, and, according to the naturalistic fallacy, would no longer be considered morally good either, as noted parenthetically in the following quotation: "Furthermore, something may be more likely to be identified as natural to the extent that its existence is perceived to be predicated upon an underlying genetic predisposition (unless the genes themselves are the product of artificial manipulation as in the case of genetically-modified products)."[17]

One might wonder whether, according to this presupposition, every human being who, for instance, at the embryo stage had been genetically modified through germline interventions would be considered non-natural and (by a naturalistic fallacy) *worse* morally speaking than a person whose genome had not been changed in that manner. Is the same to be assumed for a modification of the epigenome? Both conclusions might follow as a naturalistic fallacy from the position of strong genetic determinism and, as will be shown subsequently, from the additional assumption of epigenetic determinism. Therefore, genetic essentialism, strong genetic determinism, and epigenetic determinism are to be rejected, not only on scientific grounds but also on ethical grounds.

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[16] Ibid., 808.
[17] Ibid., 802.

2.2. Covert Genetic Determinism and Epigenetic Determinism

a) Concept

Even *moderate* or *weaker* forms of genetic determinism, which merely assume that a gene sometimes leads to the expression of certain characteristics,[18] although scientifically correct, can become problematic from an ethical perspective if they are corroborated by further assumptions. These are the assumption that, by choosing their environmental conditions, individuals themselves can influence when a gene leads to the expression of particular characteristics, and the assumption that this particular epigenetic shaping of the genes can then also be passed on to future generations. Environmental conditions include nutrition (nutri-epigenetics). Following Miranda Waggoner and Tobias Uller (*see supra* note 7), we use the term epigenetic determinism to summarize these ideas. Epigenetic determinism is also based on assumptions that are partly unconfirmed scientifically. The assumption of transmission of acquired epigenetic modifications to future generations, albeit not validated, is based primarily on studies of the effects of malnutrition on subsequent generations.[19]

The concept of epigenetic determinism thus comprises the idea of genetic determinism, extended by the findings of epigenetics and further hypotheses concerning a perceived control of one's own epigenome and the epigenome of future generations and the responsibility derived from it. The latter in particular is problematic from a scientific point of view, since a direct control of one's own health and, in particular, the health of subsequent generations, mediated via the epigenome, cannot be, or at least has not yet been, proven in humans. Before coming back to this, however, some remarks concerning the assumption of genetic determinism extended by the findings of epigenetics are in order.

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18 Resnik and Vorhaus, "Genetic Modification and Genetic Determinism" (*see supra* note 9).

19 E. W. Tobi et al., "DNA Methylation Signatures Link Prenatal Famine Exposure to Growth and Metabolism," *Nature Communications* 5 (5592), Nov. 26, 2014, DOI: 10.1038/ncomms6592.

Sebastian Schuol describes covert genetic determinism as a disguised form of genetic determinism: "Der Phänotyp wird vom epigenetisch aktivierten Teil des Genoms determiniert" (The phenotype is determined by the epigenetically activated part of the genome).[20] This indicates that a gene does not directly result in the expression of a certain trait (phenotypic trait), as genetic determinism would claim, but rather that it only results in the expression of this trait when this gene is *epigenetically activated*. Epigenetic activation refers to a specific molecular configuration of DNA. For example, a gene is epigenetically activated if the DNA has a certain methylation state, since transcription of DNA (*reading*) is, in simple terms, possible only if the base cytosine (a component of DNA) is not methylated, that is, if no methyl group is attached to the cytosine in certain cytosine-rich parts of the genome, so-called CpG islands.[21] In accordance with the current understanding of epigenetics, expressed in covert genetic determinism, the genome continues to determine the phenotypic characteristics of a person.

Both Schuol, and Waggoner and Uller (*see supra* note 7), in their respective analyses of the influence of epigenetics findings on the concept of genetic determinism in science, popular science, and society, adopt a molecular genetics notion of epigenetics that includes, for example, DNA methylation. The two analyses draw a similar conclusion: it seems that in both popular and scientific discourse, the concept of epigenetics is invoked to refute genetic determinism, but genetic determinism persists in a covert form.

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[20] Schuol, "Widerlegt die Epigenetik den Gendeterminismus?" (*see supra* note 7) 53.

[21] C. W. Hanna and G. Kelsey, "The Specification of Imprints in Mammals," *Heredity* 113 (2014): 176–83, DOI: 10.1038/hdy.2014.54. This is where epigenome editing comes in, which aims to influence the transcription of certain genes by changing the epigenome, for example, the methylation state of DNA (see table 1).

b) Critique

In the field of ethics, criticism is also leveled at the concept of covert genetic determinism.[22] It is correct from a scientific point of view that, as Schuol writes, *the phenotype is determined by the epigenetically activated part of the genome*. That is, whether a gene leads to the formation of a certain trait depends, among other things, on whether, simply put, the gene is epigenetically activated. We have described above the molecular genetic aspects of this. On one hand, however, covert genetic determinism is problematic if one assumes that humans are influenced only by their epigenetically activated genome and not, for example, also by their socialization. On the other hand, covert genetic determinism is also ethically problematic when it turns into epigenetic determinism. We define epigenetic determinism as follows:

> *Epigenetic determinism* is a combination of:
>
> (a) *Covert genetic determinism* and
>
> (b) the scientifically not validated assumption of the possibility of a voluntary influencing of one's own epigenome and the epigenome of future generations and the responsibility derived from this.

Presupposition (b) can be found in popular science texts, such as guidebooks or scientific media texts, as Schuol noted (*see supra* note 22), and in this respect has an influence on public perceptions of epigenetics. This assumption of responsibility for one's own health, and the health of future generations, based on the possibility of changing the epigenome through a deliberate choice of environmental conditions, and thus influencing the *reading* of certain genes, whereby these changes in the epigenome can be stable over several generations, cannot be confirmed scientifically. On the contrary, there are even some reasons against it. For instance, some kind of epigenetic inheritance in humans is ruled out by the fact that the epigenome is almost completely reconfigured twice during the development of egg/sperm

[22] Schuol, *Das regulierte Gen. Implikationen der Epigenetik für Biophilosophie und Bioethik* (*see supra* note 7).

cells and embryos (so-called *epigenetic reprogramming*).[23] The scientifically unconfirmed assumption (b) is nevertheless sometimes defended in discourses on epigenetics.

Thus, the concept of epigenetic determinism serves as a descriptor of the current discussions on genetics and epigenetics. Since it is based on scientifically unproven premises, the conclusions regarding responsibility for one's own health, and the health of one's own children or later generations, are not justified and are ethically problematic. Epigenetic determinism can sometimes also be detected in ethics texts (see below, section 3.2). However, an essential prerequisite for a well-founded ethical debate is that it be based on the current state of science. The current state of science provides no evidence for the intergenerational heritability of acquired epigenetic changes in humans. Therefore, it is astonishing how long arguments about the responsibility for next generations persist and are repeated in the ethical discussion of epigenetics.

The goal of creating awareness for the concepts of covert genetic determinism and epigenetic determinism is to revisit those consequences that are ethically problematic. Schuol draws attention to this problematic nature of attributions of responsibility in popular scientific discourses on epigenetics. In section 3, we will explain that precisely because of the deterministic conception of epigenetics, ethical discourses on epigenetics are analogous to discourses on genome editing.

2.3. Genetic Exceptionalism and Epigenetic Exceptionalism with Regard to Informational Self-Determination

a) Concept

Although we have characterized both strong genetic determinism and epigenetic determinism as problematic from a scientific and ethical perspective, there is some merit to the idea that

[23] Hanna and Kelsey, "The Specification of Imprints in Mammals" (*see supra* note 21).

genetic and perhaps epigenetic personal or population data should enjoy special legal protection.[24] This idea is also referred to as *genetic* or *epigenetic exceptionalism*, with genetic exceptionalism being the older and more widespread of the two concepts or ethical-legal postulates. Genetic exceptionalism is the claim for special protection of genetic data (for example, whole-genome sequencing data obtained in research or diagnostic genetic testing). This concept can be found in ethical debates but is sometimes also criticized. In what follows, we examine whether there is any justification for a critique of genetic exceptionalism. In addition, we consider the possibility of supplementing genetic exceptionalism by a requirement to provide special protection for epigenetic data as well, thus adding epigenetic exceptionalism to genetic exceptionalism.

b) Critique

Arguing Against Genetic and Epigenetic (Data) Exceptionalism

The criticism of genetic essentialism is closely related to the critique in medical ethics of the concept of genetic exceptionalism in debates about the special treatment of genetic versus non-genetic medical information, especially with regard to a higher-ranking legal claim for protection of genetic data compared to non-genetic data. This is because the concept of genetic exceptionalism would be plausible if one assumed that persons with certain genetic characteristics suffer discrimination because other persons adopt the concept of genetic essentialism and therefore discriminate against individuals with certain genetic characteristics. This would mean that third parties assumed that only the invariable genetic characteristics (almost) completely determine the nature of these persons (genetic essentialism). In order to

[24] On ethical issues related to brain data, see F. Molnár-Gábor and A. Merk, "Spotlight. Die datenschutzrechtliche Bewertung von Neurodaten," in Fehse et al., *Fünfter Gentechnologiebericht*, 360–70; on big data and personalized medicine, see E. C. Winkler and B. Prainsack, "Big Data in der personalisierten Medizin—ethische Herausforderungen und Lösungsansätze," in Fehse et al., *Fünfter Gentechnologiebericht*, 371–400.

avoid discrimination based on this assumption, it would be necessary to provide special protection for genetic data compared to other medical or personal data against access by third parties.[25] Yet, since genetic essentialism in fact has proven to be false, arguing that genetic data should enjoy a higher level of protection than non-genetic data would in fact be scientifically implausible. This is because not only genetic but also epigenetic and other information about individuals and groups of individuals is highly informative—for example, with regard to sensitive characteristics of these individuals. Charles Dupras and Eline Bunnik offer numerous examples for this usefulness, including the re-identifiability of individuals on the basis of both their genetic and non-genetic data.[26] The authors explicitly oppose genetic exceptionalism, and instead advocate a "multi-omic contextualism." Within this contextualism approach, safeguarding different research data does not depend on which data type it belongs to. Instead, it is a matter of how sensitive the data are in each case, and how dire the consequences of data misuse would be.

In earlier versions of their contextualism model, Dupras and colleagues have already pointed out that the special protection claim of genetic data (genetic exceptionalism) must be complemented by a special protection claim of epigenetic data, as these are equally sensitive.[27] Dupras's and Bunnik's more recent contextualism model is also based primarily on an analysis of genetic and epigenetic data, yet Dupras and Bunnik[28] implicitly reject not

[25] M. J. Green and J. R. Botkin, "'Genetic Exceptionalism' in Medicine: Clarifying the Differences between Genetic and Nongenetic Tests," *Annals of Internal Medicine* 138, no. 7 (2003): 571–75, DOI: 10.7326/0003-4819-138-7-200304010-00013.

[26] C. Dupras and E. M. Bunnik, "Toward a Framework for Assessing Privacy Risks in Multi-omic Research and Databases," *The American Journal of Bioethics* 21, no. 12 (2021): 46–64, DOI: 10.1080/15265161.2020.1863516.

[27] C. Dupras et al., "Epigenetic Discrimination: Emerging Applications of Epigenetics Pointing to the Limitations of Policies against Genetic Discrimination," *Frontiers in Genetics* 9 (2018), 202, DOI: 10.3389/fgene.2018.00202; and C. Dupras et al., "Selling Direct-to-Consumer Epigenetic Tests: Are We Ready?," *Nature Reviews Genetics* 21 (2020): 335–36, DOI: 10.1038/s41576-020-0215-2.

[28] Dupras and Bunnik, "Toward a Framework for Assessing Privacy Risks" (*see supra* note 26).

only genetic but also epigenetic exceptionalism.[29] Their argument against these two concepts is that other types of data, depending on the context, have a similarly high sensitivity and therefore a similarly high demand for protection as genetic and epigenetic data.

Arguments in Favor of Genetic and Epigenetic Exceptionalism

The demand for genetic exceptionalism is initially supported by the entirely justified assumption—even without the need to advocate for strong genetic determinism—that genetic data have a particularly high informative value. On one hand, genetic data often allow predictive statements—for example, concerning the risk for the occurrence of a certain disease. On the other hand, they have an informative value that extends beyond the realm of the individual to genetically related family members. However, Dupras and Bunnik note that these two properties (predictivity and informative value with respect to third parties) could also apply to non-genetic data. As an example, they cite epigenetic variants shared by different members of a social community.[30] In addition, it could be that a combination of epigenetic and genetic data increases the risk of re-identifiability, which is why it should be considered to complement a genetic exceptionalism with an epigenetic exceptionalism.

Implications of Strong Genetic and Epigenetic Determinism for Genetic and Epigenetic Exceptionalism

Nanibaa' Garrison and colleagues point out that there are few proponents of genetic exceptionalism within ethical discourse at present.[31] However, the following argument supports the case for genetic exceptionalism: While it is true that genetic determinism has

[29] K. Alex and E. C. Winkler, "Is Dupras' and Bunnik's Framework for Assessing Privacy Risks in Multi-omic Research and Databases Still Too Exceptionalist?," *The American Journal of Bioethics* 2, no. 12 (2021): 80–82, DOI: 10.1080/15265161.2021.1991039.

[30] Dupras and Bunnik, "Toward a Framework for Assessing Privacy Risks" (*see supra* note 26), 5.

[31] N. A. Garrison et al., "Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism," *The American Journal of Bioethics* 19, no. 1 (2019): 51–63, at 53, DOI: 10.1080/15265161.2018.1544304.

been scientifically disproven, ethics should not turn away from the subject too soon. For if the concept is spread in popular scientific discourse, and if many people continue to believe that our genes largely determine us, then they will act accordingly. As a result, this misperception could continue to cause people to be discriminated against. If so, ethics must continue to deal with the implications of these false assumptions.

So, to argue that genetic health care and research data are entitled to special protection, it is only necessary to assume that the notion of strong genetic determinism or genetic essentialism is prevalent in society—more precisely, that it prevails among third parties who might discriminate against individuals on the basis of their genetic characteristics. However, it is not a necessary (but possibly a sufficient) condition to be a proponent of the assumption of strong genetic determinism or essentialism in order to support genetic exceptionalism. The same applies, moreover, to ethically problematic ideas about epigenetics. As long as the opinion prevails that, due to epigenetic controllability of gene regulation, individuals are to be held responsible for their own health, ethics must deal with the social consequences of this assumption. This would include the demand to place not only genetic but also epigenetic data under special protection in order to avoid discrimination on the basis of these data (epigenetic exceptionalism).

The aspect of heredity is also important here. While genetic determinism seems justified at least insofar as genetic information is indeed inherited, it appears that the assumption of heritability as part of epigenetic determinism serves a crucial role in the ethical discourse on epigenetics as well, yet it differentiates the significance of genetic and epigenetic information, and possibly underlines the exceptional claim to protection of genetic data (genetic exceptionalism).

However, calls for genetic and epigenetic exceptionalism would have to be accompanied by efforts to raise public awareness about the scientifically and ethically problematic assumptions of strong genetic and epigenetic determinism. This is because false

assumptions regarding epigenetics lead to ethically problematic attributions of responsibility (epigenetic determinism). False assumptions regarding genetics (strong genetic determinism) can lead, for example, to a naturalistic fallacy that labels everything genetic as natural and everything natural as good, or they can result in discrimination against individuals with certain genetic traits. After all, without this critical understanding of the concepts examined here, it is possible that calls for genetic and epigenetic exceptionalism in relation to the handling of genetic and epigenetic data could reinforce the problematic assumptions of strong genetic and epigenetic determinism. Therefore, the present chapter aims to raise awareness of a critical approach to explicit and implicit -isms related to ideas about genetics, epigenetics, and gene technology.

3. Ethical Discourse about Epigenetics and Genome Editing—Similarities and Discrepancies in Key Aspects

3.1. *Determinism*

The deterministic understanding outlined in the previous section has the effect that debates on ethical aspects of genetics and epigenetics display strong parallels to the ethical discourse on the therapeutic use of genome editing in humans. The main parallel derives from the relevance of the reference to a possible genetic or (scientifically unverified) epigenetic inheritance and the responsibility derived from this for future generations.

In the ethical controversy on genome editing, we encounter divergent positions regarding the question of how the aspect of heritability of germline interventions should be judged ethically. There are positions which start from a moral imperative for research into therapeutic or even *enhancing*[32] applications of germline genome editing,[33] as opposed to

[32] On the concept of an enhancing germline intervention, see Birnbacher, "Gentechnisches Enhancement" (*see supra* note 8).

[33] J. Savulescu et al., "The Moral Imperative to Continue Gene Editing Research on Human Embryos," *Protein Cell* 6, no. 7 (2015): 476–49, DOI 10.1007/s13238-015-0184-y.

positions that call for a moratorium with regard to research into genome editing on embryos.[34] Therapeutic modification of the genome is thus associated with high hopes of positive effects that last over several generations (for example, the hope of no longer passing on a genetically linked disease that has occurred frequently within a family in the past). However, fear of serious negative consequences that could also be passed on to multiple generations is also central to debates on genome editing. Part of the explanation for these extreme positions (imperative vs. moratorium) in the discourse on genome editing of embryos can be found in the special significance of intervening in the genome because of the assumption of genetic determinism.

3.2. *Complexity within the Question and Dissolution of Boundaries*

Another common feature of the discourses on genetics and genome editing as well as on epigenetics is the difficulty of evaluating these topics ethically. This difficulty arises from the complexity of the scientific premises, especially with regard to the dissolution of clear causal relationships between gene or genome, epigenome, and environment. There is ambiguity about what falls under the term "heredity" as a consequence of those boundary dissolutions. For example, Tim Lewens[35] and Stephan Guttinger[36] analyze genome editing from an ethical perspective with explicit reference to findings in epigenetics, and they derive the complexity of the question of an ethical analysis of genome editing from a postgenomic understanding of heredity.

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[34] E. S. Lander et al., "Adopt a Moratorium on Heritable Genome Editing," *Nature* 567 (7747) (2019): 165–68, DOI: 10.1038/d41586-019-00726-5. Of the 61 position papers on genome editing surveyed by Carolyn Brokowski that appeared between 2015 and 2018, only 5 % explicitly oppose such a moratorium: C. Brokowski, "Do CRISPR Germline Ethics Statements Cut It?," *The CRISPR Journal* 1, no. 2 (2018): 115–25, DOI: 10.1089/crispr.2017.0024.

[35] T. Lewens, "Blurring the Germline: Genome Editing and Transgenerational Epigenetic Inheritance," *Bioethics* 34, no. 1 (2020): 7–15, DOI: 10.1111/bioe.12606.

[36] S. Guttinger, "Editing the Reactive Genome: Towards a Postgenomic Ethics of Germline Editing," *Journal of Applied Philosophy* 37, no. 1 (2020): 58–72, DOI: 10.1111/japp.12367.

However, the possibility to modify the genome or the epigenome by means of genetic engineering could already complicate concepts of genetic inheritance and epigenetic causation and dissolve previously existing boundaries, even if there is no indication of a connection between genetic and epigenetic causation. This is the case when the intervention in the genome or epigenome is described as an *artificial* alteration of *natural* genetic and epigenetic functional relationships. The ethical relevance of the difference between *naturalness* and *artificiality* in this context depends, among other things, on whether a naturalistic fallacy occurs (see 2.1). What has also been discussed in medical ethics is the question of whether an alteration of genetic information in the context of assisted reproductive technologies (ARTs) has an impact on the concept of genetic parenthood.[37] Given that genome editing might be used as an ART in the future[38] and that genetic information is altered in this process as well, Monika Piotrowska's question in the article "Why is an egg donor a genetic parent, but not a mitochondrial donor?"[39] could be complemented by the question whether genome and epigenome editing on embryos or fetuses also have consequences for the concept of genetic parenthood.

Dissolving the boundaries between genetic and non-genetic causation creates a complex baseline, both scientifically and ethically, for the analysis of epigenetics and genome editing. According to Sofia Falomir, this results in the need for the epigenetics discourse to also dissolve the boundaries of the disciplines in order to analyze epigenetics scientifically.[40] The same is true for discussions on genome editing, which, especially due to the notion of

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37 M. Piotrowska, "Why Is an Egg Donor a Genetic Parent, but Not a Mitochondrial Donor?," *Cambridge Quarterly of Healthcare Ethics* 28, no. 3 (2019): 488–98, DOI: 10.1017/s0963180119000410.

38 National Academy of Sciences et al., *Heritable Human Genome Editing: Consensus Study Report* (Washington, DC: National Academies Press, 2020).

39 Mitochondria are cell organelles that are responsible for the energy supply of the cell. They are inherited from the mother's egg cell and contain their own DNA (mtDNA). In the case of certain diseases caused by nonfunctional mitochondria, ARTs can be used in various ways to ensure that the mitochondria are exchanged for those of a donor.

40 S. Falomir, "Epigenetics and Metaphor: Language of Limits," *Technoethic Arts* 16, no. 3 (2018): 259–302, DOI: 10.1386/tear.16.3.295_1.

(covert) genetic determinism, must always be considered from multiple disciplinary perspectives at the same time, so that deterministic notions can be scientifically tested and their ethical consequences highlighted. The need for an interdisciplinary approach is thus common to discourses on epigenetics as well as on genome editing.

3.3. *Domains of Discourse on Epigenetics: Heritability, Responsibility, Justice*

a) Heritability and Responsibility

In the ethical discourse on epigenetics, the question of responsibility is addressed. For example, a research report on epigenetics from the Berlin-Brandenburg Academy of Sciences and Humanities , cited at the beginning of this chapter, states: "Besondere Brisanz hat die Frage, in welchem Maß es eine epigenetische Verantwortung des Individuums für die Gestaltung der Lebensumstände nachfolgender Generationen gibt" (The question of the extent to which individuals have an epigenetic responsibility for shaping the living conditions of subsequent generations is particularly explosive).[41]

Schuol, in his ethical analysis of the popular scientific discourse on epigenetics, also points to the centrality of the question of responsibility:

> On the part of popular science guides . . . three main topics are discussed. . . . 1. the epochal change initiated by epigenetics and the replacement of geneticism, 2. the thereby promoted topic of lifestyle-related controllability of gene regulation, and 3. areas of responsibility resulting from this controllability. . . . The statement that a *transgenerational responsibility* is connected with epigenetics was narrowed down: Several reasons speak against an epigenetic inheritance in humans.[42]

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41 J. Walter and A. Hümpel, eds., *Epigenetik. Implikationen für die Lebens und Geisteswissenschaften* (*see supra* note 6), 28.

42 Schuol, *Das regulierte Gen. Implikationen der Epigenetik für Biophilosophie und Bioethik* (*see supra* note 7), 368–71, emphasis in original: "Auf Seiten populärwissenschaftlicher Ratgeber werden . . . drei Hauptthemen diskutiert. . . . 1. der durch die Epigenetik eingeleitete Epochenwandel und die Ablösung von einem Genfatalismus, 2. das dadurch beförderte Thema lebensstilbedingter Steuerbarkeit der Generegulation und 3. sich in Folge dieser Steuerbarkeit ergebende Verantwortungsbereiche. . . . Die Aussage, dass mit der

This is in line with the concept of epigenetic determinism described above. Schuol, as well as Jörn Walter and Anja Hümpel, draws attention to difficulties with the assumption of epigenetic determinism, as the latter is based on scientific presuppositions that cannot be confirmed. Nevertheless, the assumption of a *lifestyle-related controllability of gene regulation*, which, as explained above, includes, for example, nutrition, coupled with the assumption of an *epigenetic inheritance*, can be found not only in popular science but also, as a consequence, within social discourse. But such an epigenetic determinism can also be identified within the ethical discourse on epigenetics.

As a result, ethical analyses of epigenetics are widely divergent. There are two basic approaches. Either it is assumed that epigenetic inheritance and responsibility for future generations do exist.[43] Or notions about an epigenetic foundation of intergenerational epigenetic responsibility are strongly rejected.[44] Only the latter, as shown above, corresponds to the current scientific state of the art. The assumption of epigenetic inheritance and responsibility for future generations is therefore invalid as long as it is not scientifically proven.

b) Justice

In epigenetics discourse, the aspect of responsibility for future generations resulting from the assumption of epigenetic determinism is also referred to as *intergenerational justice*. Since epigenetic determinism is based on the assumption that it is possible to influence the epigenome, and thus one's own health, through a conscious choice of environmental conditions, the epigenetics discourse calls for *environmental justice* (healthy environmental

Epigenetik eine *transgenerationale Verantwortung* verbunden sei, wurde eingegrenzt: Gegen eine epigenetische Vererbung beim Menschen sprechen mehrere Gründe."

[43] P. Bode, "Identität und Nichtidentität. Intergenerationale Gerechtigkeit als Gegenstand einer Ethik der Epigenetik," in Heil et al., *Epigenetik. Ethische, rechtliche und soziale Aspekte* (*see supra* note 7), 59–73.

[44] For example, Schuol, "Widerlegt die Epigenetik den Gendeterminismus?" (*see supra* note 7); and J. Y. Huang and N. B. King, "Epigenetics Changes Nothing: What a New Scientific Field Does and Does Not Mean for Ethics and Social Justice," *Public Health Ethics* 11, no. 11 (2018): 69–81, DOI: 10.1093/phe/phx013.

conditions for all). Supplemented by the demand for equitable access to health care, there is a triad: "environmental justice, intergenerational equity, and equitable access to healthcare."[45]

The aspect of environmental justice marks a central difference between the discourses on genome editing and on epigenetics. Here it becomes clear that discussions on epigenetics are more likely to be located in the field of public health ethics, whereas the debate on genome editing, although also partly carried out in this field with reference to distributive justice, predominantly adopts an approach based on the perspective of individual ethics. Thus, the three-part demand for environmental justice, intergenerational justice, and equitable access to health is to be understood primarily as a demand at the institutional level. Dupras and colleagues therefore attribute responsibility for one's own health and the health of future generations not to the individual but to the institutions of the state. "It would thus be unfair to blame the poor for being malnourished or living in toxic environments, factors that, through epigenetics, can negatively affect their own as well as their children's health."[46] It is important to point out once again that from a scientific point of view, the assumption of some kind of epigenetic inheritance in humans, which is reflected in this quotation, cannot be substantiated.

3.4. *Domains of Discourse on Genome Editing: Safety, Consent, Future Generations*

The demand for equitable access to promising gene therapy methods is also central to debates on genome editing.[47] In addition, the relevance of the aspect of inheritance in particular points to a further commonality with discourses on epigenetics. Debates on genome editing are predominantly concerned with ethical questions arising from germline interventions, and have

[45] C. Dupras and V. Ravitsky, "The Ambiguous Nature of Epigenetic Responsibility," *Journal of Medical Ethics* 42, no. 8 (2016): 534–41, at 538, DOI: 0.1136/medethics-2015-103295.

[46] C. Dupras et al., "Epigenetics and the Environment in Bioethics," *Bioethics* 28, no. 7 (2014): 327–34, at 333, DOI: 10.1111/j.1467-8519.2012.02007.x.

[47] I. van Dijke et al., "The Ethics of Clinical Applications of Germline Genome Modification: A Systematic Review of Reasons," *Human Reproduction* 33, no. 9 (2018): 1777–96, DOI: 10.1093/humrep/dey257.

from their very beginning focused on the responsibility for future generations.[48] The call for a moratorium on research into germline genome editing thus arises from concerns that the effects of intervening in the genome at the germline level (for example, on embryos) can be inherited by future generations.

a) Safety

Since the effects of genome editing with a therapeutic intention are not fully known in advance, a serious safety issue of germline genome editing is that any adverse effects can be passed on to countless downstream generations. For this reason, one necessary precondition for such an intervention is generally referred to as sufficient safety.[49] The following recommendation from U.S. and UK scientific societies on germline genome editing provides an example:

> Before any attempt to establish a pregnancy with an embryo that has undergone genome editing, preclinical evidence must demonstrate that heritable human genome editing (HHGE) can be performed with sufficiently high efficiency and precision to be clinically useful. For any initial uses of HHGE, preclinical evidence of safety and efficacy should be based on the study of a significant cohort of edited human embryos and should demonstrate that the process has the ability to generate and select, with high accuracy, suitable numbers of embryos that:
>
> - have the intended edit(s) and no other modification at the target(s);

[48] E. Agius and S. Busuttil, eds., *Germ-Line Intervention and Our Responsibilities to Future Generations* (Dordrecht: Spinger/Kluwer, 1998).

[49] S. Holm, "Let Us Assume That Gene Editing Is Safe: The Role of Safety Arguments in the Gene Editing Debate," *Cambridge Quarterly of Healthcare Ethics* 28, no. 1 (2019): 100–11, DOI: 10.1017/S0963180118000439.

- lack additional variants introduced by the editing process at off-target sites—that is, the total number of new genomic variants should not differ significantly from that found in comparable unedited embryos;
- lack evidence of mosaicism introduced by the editing process;
- are of suitable clinical grade to establish a pregnancy; and
- have aneuploidy rates no higher than expected based on standard assisted reproductive technology procedures.[50]

b) Consent

In addition to safety, a particularly significant aspect in the ethical discourse on genome editing concerns the fact that, on one hand, a germline intervention is necessarily carried out without the consent of the person concerned, insofar as it is performed on embryos; embryos of course are not yet capable of giving consent. On the other hand, the intervention also has effects on potential offspring of these embryos due to its hereditary nature. These offspring also cannot consent to the intervention, since they do not yet exist. Thus: "issues of consent and threats to the autonomy of future generations are coming to the forefront of the debate."[51]

Linked to the problem of safety, the consent issue seems particularly relevant for genome editing on embryos. This is because it is seemingly impossible to resolve the problem of uncertainty about potentially serious negative consequences before the technique is first used on human embryos.[52]

That a medical intervention sometimes has to be carried out without the consent of the person concerned is a problem well known from other contexts—for example, in the

[50] National Academy of Sciences et al., *Heritable Human Genome Editing* (*see supra* note 38), 142, recommendation 5.

[51] R. L. Mintz et al., "Will CRISPR Germline Engineering Close the Door to an Open Future?," *Science and Engineering Ethics* 25, no. 5 (2019): 1409–23, DOI: 10.1007/s11948-018-0069-6.

[52] Guttinger, "Editing the Reactive Genome" (*see supra* note 36).

treatment of children, unconscious persons, and other non-consenting persons. In the debate on genome editing, however, the problem of consent is particularly central, since medical interventions on embryos and with relevance for future generations are non-typical cases in which consent cannot be obtained. For non-consenting persons, the following generally applies:

a) at the time of an intervention to which they cannot consent, they already exist;
b) they have representatives who can make a decision in their interest (in the case of children, these are often their parents);
c) the intervention they cannot consent to is associated with more predictable risks than a first clinical use of genome editing would be (aspect of safety, see above); and
d) their existence does not depend on the intervention itself.

These four conditions do not apply to embryos on which genome editing is performed, nor to their potential offspring, that is, to future generations. A heritable intervention in the genome of embryos or germ cells is therefore problematic even if sufficient safety could be ensured, since even then the other three of the consent-related aspects (a, b, and d) do not apply.

c) Effects on Embryos and Future Generations

Despite the centrality of the consent problem in the current discourse on genome editing, there is also criticism of what it means. This is because this position omits reference to how such consent could be obtained.[53] However, within debates on genome editing, the problem of heritability of germline interventions is also seen as problematic for reasons other than the inability of embryos and future generations to consent.

[53] G. Cavaliere, "Genome Editing and Assisted Reproduction: Curing Embryos, Society or Prospective Parents?," *Medicine, Health Care, and Philosophy* 21, no. 2 (2018): 215–25, at 218, DOI: 10.1007/s11019-017-9793-y.

Depending on the moral status of the embryo, it might be impermissible to use the embryo for genome editing research and to discard it afterwards. However, even if the embryo is not discarded after genome editing but is transferred for pregnancy, an intervention in its genome may be problematic for ethical reasons. This is partly based on the right of the embryo and its potential offspring to an open future.[54] Linked to this is the problem of a negative influence on the relationship between the generations, whereby one generation influences the composition of the genome of another generation, which is to be judged negatively from an ethical point of view.[55]

The moral status of the embryo is relevant not only for debates about genome editing at the germline level, but also in relation to so-called prenatal diagnosis (PND) and preimplantation genetic diagnosis (PGD). In PGD, embryos are genetically examined, and those among them that are supposedly "healthy" are then selected and implanted with the aim of establishing a pregnancy. In the ethical discourse on genome editing, it is sometimes assumed that genome editing could be an alternative to PGD. Some works therefore compare PGD and genome editing and come to different conclusions regarding which of the two reproductive technologies would be ethically preferable.[56] However, this comparison may be obsolete. After all, reproductive use of genome editing without subsequent preimplantation genetic diagnosis and embryo selection seems to be out of the question for reasons of safety.[57] If one assumes that the moral status of the embryo prohibits the selection of embryos in the

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54 Going back to Joel Feinberg's concept of a "right of the child to an open future," see in the genome editing discourse, for example, Mintz et al., "Will CRISPR Germline Engineering Close the Door to an Open Future?" (*see supra* note 51).

55 This reasoning traces back to Jürgen Habermas, *Die Zukunft der menschlichen Natur. Auf dem Weg zu einer liberalen Eugenik?* (Frankfurt am Main: Suhrkamp, 2001). It can be seen in the debate comparing genome editing and preimplantation genetic diagnosis in C. Rehmann-Sutter, "Why Human Germline Editing Is More Problematic Than Selecting between Embryos: Ethically Considering Intergenerational Relationships," *The New Bioethics* 24, no. 1 (2018): 9–25, DOI: 10.1080/20502877.2018.1441669. See also D. Lanzerath, "Ethische Kriterien und Argumente im Wandel der Zeit," in Hucho et al., *Vierter Gentechnologiebericht* (*see supra* note 8), 103–28, at 121.

56 Rehmann-Sutter, "Why Human Germline Editing Is More Problematic Than Selecting between Embryos" (*see supra* note 55).

57 National Academy of Sciences et al., *Heritable Human Genome Editing* (*see supra* note 38).

context of assisted reproductive medicine, then both PGD and genome editing would not be acceptable.

4. Conclusion and Outlook

In summary, ethical arguments relating to future generations and justice play a central role in the discourse on both epigenetics and genome editing. We began this article by analyzing and critically discussing the following concepts: genetic determinism, which is the basis of genetic essentialism; epigenetic determinism; and genetic and epigenetic exceptionalism. The discussion of the ethical discourse on epigenetics shows that the notion of epigenetic determinism can sometimes be found not only in popular scientific discourse but also in ethical discourse. Ethical debates on epigenetics, however, often distance themselves from this deterministic understanding. As a result, the focus of ethical discourse on epigenetics shifts from responsibility for one's own health and that of future generations to justice. What is meant here is justice, for example, with regard to access to healthy environmental conditions, regardless of whether these contribute to health with or without epigenomic mediation.

An analysis of the discourse on genome editing reveals that it is primarily germline interventions that are being ethically scrutinized, and that the focus here is on the aspect of heredity. The question is whether this is accompanied by an implicit genetic determinism or even a genetic essentialism: the determinism could lie in the centrality of the aspect of heritability, since only genetic information is inherited. Does the aspect of heredity and the modification of the genome play a more decisive role in debates on genome editing than the problem of safety? Is the problem that embryos and their potential offspring cannot consent to germline interventions given such a high priority because these are genetic interventions?

Ethical criticism of germline genome editing (research) is sometimes based on arguing that safety risks are too high, and that to protect the embryo, (consumptive) research on

human embryos which could minimize these safety risks should not be done. Alternatively, ethical criticism of germline genome editing (research) might be based on genetic determinism or genetic essentialism. This is the case if genome editing is rejected essentially because of the problem of heritability of genetic interventions on the germline level. This seems to imply at least a kind of weak genetic essentialism. This is because the distinctiveness of the disposition of one generation over another would, in this line of reasoning, be derived from the fact that it is a genetic disposition.[58] Following such argumentation, a fundamentally non-genetic influence on future generations would thus be relevant only if it were a matter of an influence on the genome mediated, for example, via the epigenome.[59]

Under such a presupposition of strong genetic determinism supplemented by epigenetic determinism, not only genome editing but also epigenome editing would be ethically relevant precisely because it, too, would have an influence on the genome. How this influence of genome editing, and epigenome editing is ethically evaluated in each case therefore depends initially on whether the assumptions of genetic and epigenetic determinism are advocated. These assumptions are increasingly viewed critically in ethical discourse because they cannot be confirmed scientifically. In popular scientific debates in particular, however, they seem to persist, which ultimately also influences the public discussion. Since a broad public discussion is required especially for genome editing, a reflective handling of the different -isms analyzed in this chapter is central.

[58] We would like to thank Christiane Woopen for a critical discussion of this aspect.
[59] Guttinger, "Editing the Reactive Genome" (*see supra* note 63), 67.