OPINION 138

EUGENICS: WHAT EXACTLY ARE WE TALKING ABOUT?

NATIONAL CONSULTATIVE ETHICS COMMITTEE
FOR HEALTH AND LIFE SCIENCES

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This Opinion was adopted unanimously by the committee members during the plenary assembly on 20 May 2021.

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ERRATUM

The definition of eugenics on page 13 is proposed by the CCNE and is not based on the work of the Council of State. This definition appeared in the glossary on p.41-42 of CCNE Opinion 133 on the ethical challenges of genome editing.

INTRODUCTION

CCNE Opinion 133, which was published on 3 March 2020, addressed the ethical challenges of genome editing. In its conclusion, this opinion raised a fundamental ethical question associated with the use of the CRISPR/Cas9 "genetic scissors" technology[1]: *"Where genetic modifications can be transmitted to human descendants, the extent of the technical and scientific uncertainties surrounding the short and long-term consequences warrants, as things currently stand and in addition to French legislation, an international moratorium prior to any implementation. Even if such technical and scientific uncertainties are reduced, there remains the major ethical issue of individual care that does not come under a eugenics approach for transforming the human species*[2]." »

This Opinion aims to continue the discussions sparked by the prospects of genomic medicine by taking a closer look at a potential "abuse of eugenics"[3].
In addition to the specific reasons that prompted the CCNE to address this topic, the use of the term "eugenics" resurfaced in the public domain and the press during the parliamentary debate on revising the country's bioethics law, which was especially provoked by the question of using preimplantation genetic diagnosis for aneuploidy (PGD-A)[4] in the context of medically assisted reproduction[5].
These two contextual factors spawned the creation of a working group (the members are listed in Appendix 1) to examine both contemporary medical practices and future medical practices from a eugenic perspective. First of all, it is worth looking at what the term actually means.

The word "eugenics" comes from the Greek *eu-* ("good") and *genos* ("birth" or "race"), which is linked to the Indo-European root °*gen(e)-, °gne-* ("beget" and "be born").[6] This etymology already draws attention towards the practices associated with reproduction. However, as philosopher Jean Gayon points out: "*A problem of definition arises, and any attempt to avoid using an artifice of language would be futile. Eugenics is not actually the name of a scientific or philosophical concept, but the culmination of a winding historical reality*,"[7] which needs to be retraced in broad strokes to identify its specific features and reveal any areas that strike a chord with the current situation.

In addition, the use of this word today is often what Jérôme Goffette describes as a "rhetorical amalgam"[8]. As Pierre-André Taguieff points out, its historical significance

[1] Refer to the glossary in Appendix 3.
[2] National Ethics Advisory Committee (2020). Opinion 133: Ethical Challenges of Gene Editing: Between Hope and Caution, 46 p. (see p. 38).
[3] Opinion 133, *op. cit* . p. 29: *"Is any modification to the germline genome still unacceptable? Has this not already been used to treat serious and incurable illnesses? Ethical questions must be asked in such cases and should lead to discussions about the limits of these approaches to avoid any eugenic abuses*."
[4] Refer to the glossary in Appendix 3.
[5] National Assembly, Special committee responsible for examining the bioethics bill, Report no. 33 of the session of 9 September 2019 (p. 57). The Bioethics Law (no. 2021-1017) was enacted on 2 August 2021.
[6] Rey A. (2012). Historical dictionary of the French language*, Le Robert (3 volumes).*
[7] Gayon J. (1999). Eugenics: yesterday and today, *Médecine/Sciences*, 15 (no. 6-7), I-VI.
[8] Goffette J. (2013). Prenatal testing and eugenics: philosophical and historical reflections, *Rev. med. perinat*, 5, 164-171.

constitutes "an interpretative bias that makes it hard to take a neutral approach to the phenomenon."[9] That explains why this opinion approaches the concept of ethics as an ethics of language, based on a word that has become so deafening that it runs the risk of occasionally distorting or concealing the key ethical issues underlying its associated practices. By asking the question "Eugenics: what exactly are we talking about?", the CCNE intends to revert to the correct use of the words and thereby rekindle the necessary discussions and, instead of reaching a dead end, take a historical, contemporary and forward-looking path by questioning the breaks and continuities between these three periods.

Various key figures were interviewed when preparing this opinion (refer to Appendix 2). Although this opinion follows in the footsteps of a long line of opinions dealing with similar issues in one way or another (see Appendix 4)[10], it provides an opportunity to set the record straight, particularly the historical aspects, and address the wide range of possibilities opened up by the medical practices of tomorrow's world.

[9] Taguieff P-A (2020). Eugenics, *What do I know?*, Presses Universitaires de France, 128 p. (see p.4).
[10] See Appendix 4: Changes in the use of the word "eugenics" in the CCNE's opinions.

I - YESTERDAY: A LONG HISTORY OF AMBITIONS TO IMPROVE THE SPECIES

I-1- EUGENICS BEFORE THE TERM WAS COINED

History is rife with examples of various attempts to organise human reproduction with a view to safeguarding a lineage or improving the species. For instance, cases of incest have been recorded in the ruling dynasties of Ancient Egypt and the Incas in an effort to preserve the royal blood line. Plutarch also recounts that new-born Spartans were observed by a committee of elders who condemned them to death if they were "ill-born and deformed". [11]
Even Plato sets out the following thought in *Republic*: "*The best men must cohabit with the best women in as many cases as possible, and the worst with the worst in the fewest; the offspring of the one must be reared and that of the other not, if the flock is to be as perfect as possible. And the way in which all this is brought to pass must be unknown to any but the rulers*."[12]

The Renaissance also had its share of "eugenic intuitions", particularly Thomas More's *Utopia* (1516) or the Italian Tommaso Campanella's *The City of the Sun* (1602).
Long before Darwin came on the scene, there were treatises on cosmogonic medicine in France that sang the praises of "good birth methods", such as *Callipædia*[13] by Quillet (1655) or *Conjugal Love Reveal'd* by Venette (1686), and which were aimed at future parents. However, at the end of the 18th century and the turn of the 19th century, works began to be published that were addressed at legislators rather than future parents. Their objective was to implement policies to "manufacture elites", such as *Essay on Perfecting the Human Species* by Vandermonde (1756) and *Essay on Megalanthropogenesis* by Robert le Jeune (1801).

Therefore, the seeds for eugenics were sown long before the end of the 19th century. However, Charles Darwin's theory of evolution by natural selection[14] and the fear of the human species' "degeneration" that spread through the international scientific community at that time provided fertile conditions for eugenics' development.

[11] Plutarch (c. 100) *The Lives of Illustrious Men. A. Pierron (4 volumes).*
[12] Plato (4th century BC), The Republic. J. Moreau et L. Robin.
[13] Literally, the art of producing beautiful children. "Megalanthropogenesis" was developed later, meaning the art of making children of spirit, who are destined to become great men (this is the title of an essay by Dr L. J. Robert in 1801).
[14] Darwin C. (1859), *On The Origin of Species*, 624 p. E.J-F Barbier, 624 p..

I-2- GALTON AND THE COINED TERM "EUGENIC"

The word was used for the first time by British scientist Francis Galton in 1883 in *Inquiries into Human Faculty*, where he defined it as follows: "*We greatly want a brief word to express 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 the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable that they otherwise would have had."*
Particularly inspired by observing breeding practices, Francis Galton asserted that it was possible *"to obtain by careful selection a permanent breed of dogs and horses gifted with peculiar powers [...] so it would be quite practicable to produce a highly-gifted race of men by judicious marriages during several consecutive generations*."[15]

The stated aim of eugenics is to "improve the human race".
Many conflicting strategies are put forward, and their proponents can be divided into two camps, with some scientists in favour of cross-breeding, while others are steadfastly opposed[16]. Supporters of absolute genetic determinism also challenge those who defend the influence played by the individual's social and economic background.
Above all, some proponents will head down the negative eugenics road (2), while others will adhere to positive eugenics programmes (1):

- (1) **Positive eugenics** encourages reproduction with the potential to improve the species and goes as far as social and political considerations concerning the environments that are favourable or unfavourable to the "defects" that it is ultimately aimed at eliminating.[17]
- (2) **Negative eugenics** includes measures that range from partial or complete segregation through to sterilisation[18] and even death (improperly called "euthanasia" by the Nazis, implying the grace of a "good death" for those who had not experienced a "good birth").[19]

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[15] Aubert-Marson D. (2009). Sir Francis Galton: the founder of eugenics. Médecine/Sciences, 25, 641-645.

[16] According to the article by Jacques Léonard, entitled *The origins and consequences of eugenics in France* (Annales de démographie historique, 1985, 203-214), the proponents of "ethnic cross-breeding" in France were the monogenists Serres, Quatrefages, Godron, Bertulus, Morel, Devay and Frédault, as well as such observers as Fodéré, Tourtelle, Thévenot, Hombron, Levaillant and Marit, while their opponents included Virey, Raige-Delorme, Bory-Saint-Vincent, Yvan, Jacquinot, Boudin, Bertrand, Georges Pouchet, Périer, Dally and Paul Broca (to a certain extent).

[17] For example, see Dr B.-A. Morel, in *Considerations on the endemic causes of goitre and cretinism in Rosières-aux-Salines*, 1851: "Through physical and moral treatment, we can often reconstitute the fallen or perverted elements of our humanity, so could such treatment not be applied to certain social conditions that exist outside a mental hospital?" ». In a more modern setting, positive eugenics can be illustrated by the idea of creating of a sperm bank for Nobel Prize laureates (sperm bank created in 1980 by Robert Klark Graham in the hope of achieving a long-term increase in the average intelligence of the US population).

[18] Sterilisation laws were enacted in the United States, Germany and Scandinavia with expert advice from doctors. In the United States, some 50,000 individuals were involuntarily sterilised under eugenic legislation between 1907 and 1963. The following were considered to be "socially inadequate": "the feebleminded, the insane, the criminalistic, (including delinquents and deviants), the inebriated, the diseased (tuberculosis, syphilitic diseases, etc.), the blind, the deaf, the deformed, and dependents (including orphans, ne'er-do-wells, the homeless, etc.)."

[19] In Germany, after 400,000 people had been sterilised between 1933 and 1935, the decision was taken to exterminate the mentally ill and the marginalised (1939-1942), then the Jews and Romani people in the name of a "racial hygiene" policy that the Nazis refused to distinguish from a eugenic programme.

Furthermore, the founding text of UNESCO, which was written in 1946 as part of the Preparatory Commission of the United Nations Educational, Scientific and Cultural Organisation, fully assumes the eugenic ambition, to the point of specifically defining the qualities targeted: *"While there may be dispute over certain qualities, there can be none over a number of the most important, such as a healthy constitution, a high innate general intelligence, or a special aptitude such as that for mathematics or music. At the moment, it is probable that the indirect effect of civilisation is dysgenic instead of eugenic; and in any case it seems likely that the dead weight of genetic stupidity, physical weakness, mental instability, and disease-proneness, which already exist in the human species, will prove too great a burden for real progress to be achieved. Thus even though it is quite true that any radical eugenic policy will be for many years politically and psychologically impossible, it will be important for Unesco to see that the eugenic problem is examined with the greatest care, and that the public mind is informed of the issues at stake so that much that is now unthinkable may at least become thinkable."*[20]

As far as France in particular is concerned, Alexis Carrel and Charles Richet should not be overlooked, both of whom were fervent defenders of eugenics in all its forms and even went as far as supporting *"the destruction of malformed new-born babies {and} the death penalty for eugenic purposes"* (Charles Richet)[21]. They were awarded the Nobel Prize for Medicine in 1912 and 1913 respectively. French enthusiasm for the prospects of eugenics was especially shared by the scientific community, but only rarely followed up in practice. On the other hand, Scandinavian countries and the United States carried out eugenic practices through much of the 20th century (including policies to sterilise criminals, the homeless and the mentally ill, and those policies existed until 1974 in some US states). In Germany, ministerial practices under the Third Reich, particularly relating to the "inventory of the genetic heritage", led to appalling discrimination and executions[22].

I-3- FAILED EUGENIC INTENTIONS IN FRANCE

Unlike the tragic projects put into action by certain Scandinavian countries, the United States and Germany, France never implemented the eugenics programme that had mobilised so many of its leading scientists and doctors (note that prior to the Second World War, France did not have a genetics society, but a eugenics society).
It was not until the early 1940s that French legislation incorporated a measure for the first time that has sometimes been described as eugenic although, following Jean Gayon, it can essentially be seen as a general, non-discriminatory hygiene measure[23]. This measure featured in the law of 16 December 1942, which amended Article 63 of

[20] Huxley J. (1946). *UNESCO, its purpose and its philosophy* (72 p.), Preparatory Commission of the United Nations Educational, Scientific and Cultural Organisation (see p. 23). However, it is worth noting that WHO proposed a definition of well-being at the same time that not only included the absence of disease, but also psychological, cultural and social factors, thereby complementing UNESCO's position with certain nuances.
[21] Carol A. (1996). Medicine and eugenics in France, or the dream of perfect prophylaxis (19th century to the first half of the 20th century), *Revue d'histoire moderne et contemporaine,* 43-4, 618-631. In particular, Richet entertains the idea of a "new penal colony" for dysgenic individuals: "It won't be a punishment, but a prevention." »
[22] Czech H. (2005). Public health, racial hygiene and eugenics under the Third Reich: the example of Vienna, *Revue d'Histoire de la Shoah*, 183-2, 423-440.
[23] Gayon J., "How did eugenics evolve from theory to practice?" https://www.huffingtonpost.fr/jean-gayon/pratique-eugenisme_b_3293243.html

the French Civil Code: "*the civil registrar may only proceed with publishing the notice of marriage (...) after each of the future spouses has submitted a medical certificate dated within the last month and certifying,* to the exclusion of any other indications*, that he or she has been examined with a view to marriage."*[24]. This law may have been coercive towards couples wishing to get married, but it was not coercive for doctors, who maintained their duty to doctor-patient confidentiality and their right to non-disclosure of any advice given to their patients during a one-to-one consultation. **Doctors preferred improving childbirth quality by offering advice on hygiene and best practices for raising children, rather than through exclusion[25].**

In France, Jacques Léonard writes that "the eugenics mountain has given birth to a mouse!" ». Historian Anne Carol believes that eugenics' failure to gain traction in France can be explained by the fact that **doctors were strongly represented in the French eugenics movement**. Even though they might have been seduced by the eugenic suggestion of "perfect prophylaxis", they did not lose sight of "their attachment to the liberal practice of their profession" and to the professional standards that vested them with "a fundamental role to assist the suffering." In addition, "*the uncertainties in the knowledge about heredity also prevented many doctors from venturing any further down the eugenics road*."[26]

I-4- WANING CREDIBILITY OF THE EUGENIC IDEOLOGY

Although eugenics relied on "science" to gain a foothold in society and promote a certain ideology, the development of medical genetics[27] up until the end of the 20th century helped discredit the solutions advocated by eugenics in the 19th century and the first half of the 20th century. For example, the doctrine of the genetic determinism of mental illness, which underlies traditional eugenics, was considerably weakened by the work of English psychiatrist and geneticist Lionel Penrose, who actually had the title of his chair changed from *Professor of Eugenics* (1945-1963) to *Professor of Human Heredity* (1963-1965), and by the difficulty in finding genetic variations associated with these psychiatric disorders.
Furthermore, the rising number of human diseases, for which a simple Mendelian determinism was found, belied the widely held idea that only a proportion of the population carried what used to be called genetic "defects". On the contrary, it is currently estimated that each person carries around 3 million genetic variations out of the 3 billion base pairs in the genome (ATGC). We carry an average of around 100 deleterious mutations that can lead to a risk of developing diseases[28] and a wide range of variations with minor effects which, when combined, contribute to our physical differences and our risk of disease.

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[24] That same law introduced compulsory medical check-ups during pregnancy and a health record for new-born babies issued at birth.

[25] In accordance with the Lamarckian tradition, the desire to improve the human race involves enhancing living conditions. Also worth reading is Axel Kahn's "Society and biological revolution - promoting the ethics of responsibility" (1996, Sciences en questions), which offers a reminder that French-style eugenics was sometimes also racist in nature.

[26] Anne Carol, *opus cit.*

[27] To find out more, visit: https://www.agence-biomedecine.fr/Donner-les-cles-de-la-genetique-pour-tous-lancement-du-site-genetique-medicale?lang=fr

[28] https://doi.org/10.1038/s41586-020-2308-7

As new scientific discoveries have been pioneered, the complexity involved in passing on genetic traits has shown that eradicating deleterious genetic variations by controlling reproduction is not as simple as the first eugenicists thought. In particular, the discovery of heterozygous individuals who are healthy carriers of genes with deleterious recessive mutations has revealed the complexity in transmitting hereditary diseases. Recent studies have revealed that a high number of diseases are extremely polygenic and involve thousands of genetic variations that are frequently present across the population.

The fact remains that although eugenics is touted by geneticist Theodosius Dobzhansky as the "applied science of human betterment", Pierre-André Taguieff points out that "it should be clearly dissociated from all the political manipulation that compromised its development in the 20th century" in his analysis of the lingering enthusiasm shown by a number of geneticists for eugenics in the 1960s.[29] Enthusiasm can only be tempered by memory, and it stumbles against the dilemma expressed by Dobzhansky: "*If we enable the weak and the deformed to live and propagate their kind, we face the prospect of a genetic twilight; but if we let them die or suffer when we can save or help them, we face the certainty of a moral twilight.*"[30]

It was not until the Nuremberg Trials in 1946 that the notion of eugenics-driven progress took a back seat to respect for human dignity[31]. But despite all the political and scientific factors that tend to consign eugenics to the past, the term continues to play on people's minds. A rational examination of contemporary practices will need to determine whether this degree of caution is warranted in today's world.
This examination will be based on three criteria that tend to emerge from this analysis of the historical context:

- **An aim to "improve" the human species**
- **A coercive State policy to promote this objective, based on "scientific knowledge"**
- **Individual selection criteria and procedures**

Each criterion raises its own set of alternative ethical questions:

- Why would it not be ethical to try and improve the human species? Is it the very principle of improving the human species that should be questioned, or simply the means used to achieve that goal? What are the criteria for defining a better species?
- What different forms can coercion take? Are political measures necessarily involved, or can it take more insidious forms?
- When and where does individual selection begin?

By the end of this study into the historical context, we can agree with Jean Gayon that there are *"**two reasons for not forgetting the word too quickly. As it looks to the past, it reminds us of a place where we should not return. As it takes a utopian look towards***

[29] Pierre-André Taguieff, *op.cit,* (see p. 97).

[30] Dobzhansky T. (1969). Heredity and the Nature of Man,Flammarion, Paris, 189 p. (see p. 163) S. Pasteur.

[31] The Nuremberg Code (1947) emphasises the principles of consent and personal freedom.

the possible future, it also allows us to avoid being hypnotised by it, and instead look it in the face. Words are not guilty in themselves, there are only guilty acts." [32]

This is especially true, since although the eugenic intention of the past to improve the human species has been stopped in its tracks by scientific shortcomings and stumbled into dead ends due to a flawed understanding of the laws of genetics, today's knowledge and technologies, particularly in the field of reproductive medicine, call for constant focus on the ethical issues.

[32] Jean Gayon, *opus cit*.

II - TODAY: CAN WE TALK ABOUT EUGENICS?

This question arises in light of the parliamentary discussions that have already been mentioned, which refer to eugenics as a way of painting an incriminating picture of such medical practices as preimplantation genetic diagnosis (PGD) or preconception carrier screening. Prenatal diagnostic testing can also be used as a criterion for selecting individuals, which is one of the components of eugenics. However, none of these practices seems to fulfil all the criteria previously mentioned, i.e. the aim of improving the species by means of a State policy tending to organise the individual selection process, unless questions are raised about the shift from State coercion to an insidious and, perhaps, no less vigorous form of coercion by society.

The emotional impact of the word "eugenics" makes it hard to stay objective when assessing these different practices and consider the ethical issues raised.
The increasingly widespread use of the term also runs the paradoxical risk of devaluing its meaning and trivialising the concept (this risk is even greater when considering that tomorrow's medicine could offer unprecedented opportunities for an ideology that has left an indelible mark in the history books of the last two centuries).
Just as it takes more than merely mentioning the word "eugenics" to close off all discussions and silence all forms of contradiction, refuting the term should in no way eliminate the legitimate ethical questions associated with incriminated practices[33]. The fact that the term continues to be used despite inaccuracies in its semantics shows that major ethical questions need to be addressed.

II-1 THE LAW

What the law says:
Article 16-4 of the French Civil Code
created by Law no. 94-653 of 29 July 1994

Nobody may harm the integrity of the human species (1). Any eugenic practices aimed at organising individual selection are prohibited (2). Any intervention aimed at creating a child that is genetically identical to another person, whether living or deceased, is prohibited (3) {addition of 7 August 2004}. Without prejudice to research aimed at preventing, diagnosing and treating diseases, no transformation may be made to genetic traits for the purpose of modifying the person's descendants (4).

Therefore, current French law does not use the term "eugenics" but "eugenic practices", and defines it primarily as "organising individual selection".
Such as stated here, the law opposes this practice:

- The integrity of the human species (1)
- The ban on individual selection (2)
- The ban on cloning (3)

[33] Aware of the ethical issues inherent in reproductive medicine, the CCNE decided to set up a reproductive ethics intelligence group in 2019.

- The ban on transmitting genetic traits modified by human intervention to descendants (4).

With regard to the three criteria that have been established to examine the potential relevance of eugenics, French law retains the intention of improving the human species (1) and the selection process (2), while adding cloning and germline editing (germline cells that can be transmitted to descendants).
However, it makes no distinction between the private or public nature of the condemned practices.

The French Bioethics Law also defines the legal framework for governing medical and research practices involving the human body, the embryo, procreation, genetic testing, and organ donations and transplants. The aim is to reconcile scientific advances with demands from society and the respect for human dignity and the common good.
Each stage in revising the Bioethics Law could be summarised as a confrontation between bioethics and biopower, i.e. the risk of seeing technology taking control of life, as Michel Foucault pointed out.
The Bioethics Law enacted on 2 August 2021 introduces major changes in the abovementioned areas. However, for the first time since this law and the principle for its regular review came into existence, the ethical principles and values are explicitly mentioned. Individual autonomy is reinforced through the guarantee of receiving appropriate information and multidisciplinary support, the omnipresent reminder of the need to obtain consent from each individual before any decision is taken, which underlines the affirmation of responsible autonomy as an ethical principle, and promoting solidarity while respecting individual autonomy.

II-2 CAN WE TALK ABOUT "PRIVATE EUGENICS"?

The Council of State defines eugenics as follows:
"*The term eugenics, coined by F. Galton in the 19th century, corresponds to a conservative movement in evolutionary thought that advocates the application of selection within humanity. That term now encompasses a range of methods and practices designed to improve the genetic heritage of the human species. It may* ***stem from a government's political decision*** *and result in measures to prevent immigration, segregation with control over marriages, and forced sterilisation of certain populations. It may* ***also result from individual positions*** *taken by parents or doctors as part of their refusal to accept disability and even going as far as desiring the "perfect child". Repairing a genetic alteration cannot be classed as eugenics, but lies somewhere between rejecting certain diseases and promoting racist concepts.* ***The term can be used from different perspectives that need to be clarified and enriched with ethical elements****, especially since the new genome editing technologies are likely to fuel a wide variety of trends and even demands from society."*

The question of whether eugenics can "also result from individual positions" poses a problem in terms of the criteria that have been established to define what "individual positions" mean. First of all, the intention to improve the human species cannot be attributed to future parents' individual choices. At most, they do not want to destabilise their family life, which is often thrown into disarray by the arrival of a sick or disabled

child. Jérôme Goffette also considers that eugenics includes such criteria as a population-based approach and the use of coercion[34] (these two criteria are grouped together here under the heading of a State policy aimed at improving the species). The population-based approach, combined with coercion by the State, tends to exclude the "individual positions" mentioned earlier by the Council of State from the scope of eugenics as part of prenatal diagnostic testing.
The individual nature of parental decisions, accompanied by genetic counselling based on the principle of neutrality, prevents any State ideology. During one-to-one discussions between future parents and the doctor, the idea is to encourage reproductive autonomy, according to which individuals have the inalienable right to assess for themselves the conditions under which they believe they can assume the responsibility of having children. The CCNE agrees with Jean Gayon that, by virtue of this principle of autonomy, "*parents cannot be blamed for taking the risk of having disabled children or wanting to protect themselves against that risk*."

Therefore, it seems to the CCNE that the term "private eugenics" contains a misunderstanding that nullifies its relevance and contributes to the semantic confusion that this opinion is attempting to dispel. The term also appears to give parents a sense of responsibility and guilt, which should not relate to their individual choices but, where appropriate, should instead be borne by society[35].

Nevertheless, the prospects offered by the various components of prenatal diagnostic testing[36] beg serious ethical questions. Jacques Testart also wonders about the potential for eugenic abuse in the methods used to sort embryos after in vitro fertilisation[37]. Didier Sicard believes that the rise in screening policies is indicative of a search for a certain level of normality in the unborn child, a kind of individual "good eugenics" that bears no relation to the collective eugenics of yesteryear. *"But what is normality? Is it desirable? After all, are disabilities not part of human diversity?"* he asks[38].

The ethical question that arises in this particular context is **free and informed consent** for parents receiving the diagnosis. It supposes that the healthcare professionals responsible for providing information and support are truly neutral, and that the information is both complete and impartial. Ultimately, this question boils down to the parents' individual decision, which cannot be totally divorced from political choices and social trends. Biologist François Gros is concerned about "the risk of genetic uniformity, normalisation and standardisation in the population." His criticism is not levelled at

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[34] Jérôme Goffette, *op. cit.*

[35] The tendency to shift the term "eugenics" towards individual responsibility is reflected in the definition provided by Dominique Stoppa-Lyonnet and Stanislas Lyonnet in *The 100 words of genetics*: "The generalised proposition for all pregnant women to undergo prenatal screening for Down's syndrome and the admissibility of requesting a termination of pregnancy where serious abnormalities are detected during an ultrasound scan or a genetic abnormality associated with a serious and incurable disease is identified have led some people to speak about a new form of eugenics. Old eugenics is State-led, coercive and population-oriented, while new eugenics is individual, liberal and family-centric" (paragraph referring to the book *The Eternal Return of Eugenics*, edited by Jean Gayon and Daniel Jacobi, PUF 2006, Paris)

[36] Prenatal diagnostic testing covers all the diagnoses made at various stages during pregnancy (PCS, PGD and PDT, refer to the glossary).

[37] Testart J. (2014). Making children tomorrow; Editions Seuil, 216 p.

[38] Sicard D. (2009). Medical science, birth and the risk of eugenics. Revue générale de droit médical, no. 31, 249-254.

individual eugenics, but social eugenics that tends to "*conform to genetic standards, whether set by specific legislation or the majority opinion.*"[39]
"*In fact, although there is no coercion and even less compulsion from the State, there is nonetheless social pressure*," notes Jérôme Goffette. In this respect, CCNE Opinion 107 on the ethical problems associated with prenatal diagnostic screening (PDT and PGD), which was published on 15 October 2009, urged that "*care should be taken to ensure that couples' choices are not threatened by an ideological climate of incitement. The pressure exerted on individuals does not necessarily come from the State. It can also come from actual society*."
Even if the sum of individual decisions is not comparable to a general policy, the State is liable if the conditions required to ensure completely free consent by the parents in the event of a prenatal diagnosis are not met. The large number of pregnancies terminated due to a prenatal diagnosis of Down's syndrome (over 95% at the present time) may be a reflection of the inadequate support and infrastructures available to future parents, as well as insidious pressure from society.

Therefore, the CCNE draws attention to the need to guarantee the prospect of genuinely free consent for future parents by developing all the necessary measures to facilitate the arrival of a child with a detected illness or disability, which is currently not the case.
These measures include:

- **Funding research projects focusing on the conditions that can be diagnosed during pregnancy in the hope of identifying predictive markers of their respective severity and developing treatments that will offer real alternatives to embryo selection and termination for medical reasons.**
- **Offering support to families with disabled children and increasing the number of suitable facilities for accommodating people with disabilities, not only minors but also adults.**
- **Helping combat the trend of prioritising specific skills and standardising behaviour, and providing appropriate education for all children that incorporates and values the different ways in which intelligence can be expressed[40].**

II-3 REPRODUCTIVE MEDICINE AND INTENTIONALITY

Today, the question of a possible resurgence in eugenic practices is primarily raised within the vast field of reproductive medicine.
Eugenics contains a long-term forward-looking vision for the entire population, whereas preconception carrier screening, preimplantation genetic diagnosis and prenatal diagnostic testing are limited to couples wishing to have children, irrespective of whether or not they are exposed to the risk of having a baby with an "especially serious" disease.

[39] Taguieff P-A, *op. cit.*, p. 101.
[40] Early 2021, the "Des moyens pour l'inclusion scolaire 13" collective warned of the catastrophic situation facing pupils with disabilities at school, some 16 years after the law on equal rights and opportunities had been enacted: https://informations.handicap.fr/a-ecole-inclusive-utopie-collectif-30343.php

Genetic testing on the general population is currently not authorised, which raises questions for certain diseases[41]. In France, research into the mutations that can cause a serious disease with recessive inheritance is only authorised when the family concerned has already had a child with the disease, whereas it should be extended to the general population as part of preconception carrier screening.
In its contribution to the revision of the country's Bioethics Law (Opinion 129), the CCNE wanted to see preconception carrier screening offered to all willing people of reproductive age, following a genetic consultation. The preconception diagnosis would be based on screening healthy carriers of the mutations responsible for causing serious monogenic, rather than polygenic, hereditary diseases. Two important precautions must be taken into consideration, i.e. the need for competent medical support and great care in the case of variants of uncertain significance.

In case of monogenic autosomal recessive diseases[42], embryo selection and terminations for medical reasons only eliminate the embryos carrying a disease and not the heterozygotes, which are healthy carriers of a mutated gene. Therefore, prenatal diagnostic testing techniques reduce the number of ill babies, but do little or nothing to lower the frequency of mutated genes in the general population. On the contrary, since these techniques allow a greater number of healthy carriers to think about pregnancy without running the risk of giving birth to a seriously ill baby, they tend to favour the transmission of mutated recessive genes. On the other hand, in case of autosomal dominant diseases (see glossary), only one of the two genes (from the mother or father) needs to be mutated for the disease to develop.
As a result, embryo selection, which may follow PDT or PGD, eliminates both the affected embryo and the gene carrying the mutation that causes the disease. This could lead to a reduction in the frequency of genes carrying dominant mutations in the general population. However, de novo mutations (neomutation) may appear in the gametes (see glossary) of either parent, leading to the birth of a child carrying the disease if the de novo mutation is dominant and deleterious, while any form of preconception carrier screening would not have been able to predict such mutations.
The rapid and promising development of genome editing technologies (such as CRISPR/Cas 9 - see glossary) offers the hope of curing these children when the disease that they are carrying is discovered in the early stages. Jean-Louis Mandel insists on the need to broaden the spectrum of diseases detected in neonates with the aim of using early screening to deliver fast and appropriate solutions[43].

Therefore, in the eyes of the law, prenatal diagnostic testing does not undermine the "integrity of the species" and does not infringe the ban on transmitting modified genetic traits to descendants. Their intentions are categorically different to the clearly established intention of eugenics. Nevertheless, these practices bring up the issue of "indi-

[41] Refer to the hearing with Jean-Louis Mandel, Honorary Professor at the Collège de France, Chair of Human Genetics, before the National Assembly on 30 October 2018: "*I will address the technical feasibility as well as the potential and, in my view, proven benefits of screening for certain genetic diseases among the general population, and not just in families where a child is afflicted with an illness. In this respect, I will mention preconception carrier screening for a certain number of genetic diseases, not all of them, but serious illnesses affecting children, such as cystic fibrosis and sickle cell anaemia, as well as muscular diseases like Duchenne muscular dystrophy and spinal muscular atrophy.*" "*(Fact-finding mission of the Conference of Presidents on the revision of the Bioethics Law*, National Assembly, Report no. 53).
[42] Refer to the glossary in Appendix 3.
[43] In his book entitled "*And where's the good in all that?*" (2021, Les essais Stock), Axel Kahn points out that "*the idea of a perfect genome is absurd*".

vidual selection". What measures can be taken to ensure that the decision to eliminate certain embryos following a PGD diagnosis or a termination of pregnancy does not result in preventively eliminating future individuals who would be considered to be "undesirable" in a society driven by performance and efficiency? The recommendation to develop measures to facilitate the arrival of a child with an illness or disability, while encouraging a change in attitude towards people with disabilities (see above), is once again justified.
As Jean-François Mattei points out: *"It is likely that if people with disabilities were not around, we would only be thinking superficially about the meaning of life*." »
"*Our attachment to certain values that society needs to remain fraternal*"[44] is also owed to their presence and the intimate and collective convocations produced by the question of difference.

The intentionality of using PGD to search for aneuploidy in the case of medically assisted reproduction (MAR)

One of the many bioethics debates that have raised the issue of eugenics relates to the use of preimplantation genetic diagnosis for chromosomal abnormalities (PGD-A)[45]. The idea is to open up preimplantation genetic diagnosis in MAR to search for aneuploidy (including Down's syndrome). This measure, which was ultimately dropped from the bill, was referred to as an "abuse of eugenics" during parliamentary debates[46].
However, by examining the intention behind extending PGD to encompass aneuploidy, the aim is not driven by the desire to select embryos that are more desirable than others, but select embryos that are more viable than others. On the 5th or 6th day of development, the percentage of aneuploid embryos is between 20% and 85%, depending on the age of the woman (Franasiak *et al*., 2014). They are not viable, with the exception of trisomy 13, 18 and 21[47] or sex chromosome abnormalities. These abnormalities cause implantation failures or a higher percentage of miscarriages than when the embryos are euploid. For example, in the case of monosomy X (Turner syndrome), almost 99% of embryos do not implant or result in a very early loss of pregnancy.[48]
Bearing in mind that more than 95% of couples decide to terminate the pregnancy following a prenatal diagnosis of Down's syndrome, is it more justified to make this selection at an advanced stage of pregnancy than during the preimplantation stage? It should be remembered that the MAR pathway for women is especially challenging, both for themselves and for the couple. PGD-A reduces the number of MAR attempts by restricting the number of miscarriages and also limits the risk of high hormonal exposure.
Therefore, extending PGD to aneuploidy falls within the scope of the preimplantation suitability assessment for embryonic development[49].

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[44] Mattei J.-F. (2017) Questions of conscience. From genetics to posthumanism. Les Liens qui Libèrent, 286 p.
[45] The CCNE expressed its support for extending PGD in Opinion 129, Contribution of the National *Ethics Advisory Committee to the 2018-2019 review of the Bioethics Law*
[46] See Note 5.
[47] Children with trisomy 13 or 18 can be born, but usually die soon after birth.
[48] Hook E.B., Warburton D. (2014).*Turner syndrome revisited: review of new data supports the hypothesis that all viable 45, X cases are cryptic mosaics with a rescue cell line, implying an origin by mitotic loss*. Hum Genet., 133, 417-424.
[49] This topic was covered in an opinion issued by the "Embryo and Development" group of the INSERM Ethics Committee (2021): Preimplantation suitability assessment for embryonic development - INSERM

The intentionality of ultrasound scans

A national perinatal survey (2016 report by INSERM and DREES) advises that "*the number of ultrasound scans continues to rise; in 2016, 75% of women had more than the three ultrasound scans recommended for a complication-free pregnancy, and 36% had twice as many as recommended*." Such increased monitoring of the unborn baby could raise questions if it were not explained by the following two observations:

- On the one hand, the parents' main interest during a scan is to discover their child, which differs significantly from the doctor's motivation in looking for any abnormalities.
- On the other hand, the medical eye is also trained on identifying abnormalities for therapy-related reasons (around 15% of abnormalities lead to treatment of the foetus in utero, while the announcement of an especially serious condition that is incurable at the time of diagnosis leads to a termination of pregnancy in 85% of cases)[50].

But this difference in perspective between medical practice and the parents' expectations often accentuates the shock that parents feel when they hear a worrying diagnosis, which is why it is **so important to keep the couple informed. Such information should cover both the purpose of performing ultrasound scans from a medical point of view and consistently obtaining consent for this practice, which is exactly what is needed, since ultrasound scans are so commonplace.**[51]

The ethical way to make announcements

In the case of a prenatal diagnosis that requires future parents to make a decisive choice, **it is important to nurture the ethical way in which the news is broken in accordance with the three criteria already established in CCNE Opinion 107**[52]**:**

- **Multiple options**: *"information has real ethical value when it enlightens, but does not dictate, a choice that remains open to several possible courses of action"*
- **Neutrality**: the greatest care must be taken in the words used to express the possibility of terminating the pregnancy, based on the "simple fact that even considering the possibility of terminating the pregnancy may have an incentive effect, since it implies that the doctor considers the situation to be worrying."
- **Time**: "time allows couples to think about the options without any feeling of constraint."

Provided that they are combined, these criteria also contribute to obtaining free and informed consent from the parental couple.

[50] https://www.agence-biomedecine.fr/Appendixs/bilan2016/donnees/diag-prenat/02-centres/synthese.htm
[51] French Regulation of 1 June 2015 determining the recommended best practices in terms of access, care for pregnant women and couples, and the organisation and operation of multidisciplinary prenatal screening centres in the field of prenatal and preimplantation screening: https://www.legifrance.gouv.fr/loda/id/JORFTEXT000030707965/
[52] CCNE (2009). Opinion 107: Opinion on the ethical issues relating to prenatal testing and preimplantation genetic diagnosis; Opinion_107 (ccne-ethique.fr)

Selection criteria for prenatal testing

If "especially serious" is chosen as a selection criterion for prenatal testing, this concept opens up a wide field of interpretation, as emphasised by CCNE Opinion 107:
"*Under current law, severe and incurable conditions are common reasons for terminating a pregnancy (following a prenatal diagnosis) and embryo sorting (during a PGD). However, severity is not a category that can generally be determined for a given disease. Each case needs to be judged on its own merits. The question then arises as to the extent to which couples can participate in determining the severity of a foetal abnormality or hereditary genetic condition*."

Many prenatal diagnoses also pose the problem of a high level of phenotypic variability in the expression of the identified diseases. For some diseases or infections, it is hard and sometimes impossible to anticipate the extent of the baby's disability[53]. When it comes to making a decision, we have to rely on the notion of "high probability".
This high level of phenotypic variability clearly shows that a binary categorisation of disability/non-disability fails to take adequate account of the infinite diversity of ways to be a human, which transcends and puts this categorisation into perspective.

Furthermore, if the key element that should be considered for prenatal testing and preimplantation genetic diagnosis is the severity of the disease, the ethical difficulty lies not so much in the case of very serious diseases as in the case of diseases whose clear severity may be acceptable. The problem is compounded further by advances in care and treatment, which can fortunately change the prognosis of a disease. This question has particularly been raised for cystic fibrosis, where effective treatments have been proposed, albeit with the important caveat that they are only available to a minority of patients awaiting a lung transplant due to their cost.

II-4 THE NORMAL AND THE PATHOLOGICAL

The answer to the question of knowing whether a particular phenotype resulting from a mutation is a disease or a variation differs according to the individual and the situation, as illustrated in CCNE Opinion 132 on variations in sexual development[54].
The ideal of curing or avoiding a disease therefore leads to a discussion on how to define what normal and pathological mean, which in turn raises a number of important ethical questions. What criteria can be used to define them? Biological, physiological, genetic, sociological, psychological or physical criteria? Defining what normal and pathological mean is highly variable, due to differences in perception, representation and even diagnosis (the history of medicine shows that the definition of certain diagnoses, particularly in psychiatry, may vary over time).

[53] This is the case for Down's syndrome, where expression ranges from relative autonomy to a complete lack of autonomy. Despite such variability, Down's syndrome implies 100% intellectual disability, whereas other diagnoses are based on greater uncertainty (for example, tuberous sclerosis, which is diagnosed in the 22nd week of pregnancy, can range from no expressivity to encephalopathy, with no means of prediction). Therefore, the decision to terminate a pregnancy is based on a statistical risk. Faced with such uncertainty, couples almost always decide to terminate the pregnancy, meaning that there is no way of knowing the actual percentage of cases (the statistical risk prevents real statistics from being established).
[54] CCNE Opinion 132. avis_132.pdf (ccne-ethique.fr)

In his book entitled "*The Normal and the Pathological*", Georges Canguilhem considers that illness cannot be defined objectively, but that it can be understood from the viewpoint of the patient, who is his/her own "norm"[55].
In addition, the aim of improving quality of life leads to questions about the way in which quality of life is assessed. On the one hand, many scales are used to assess quality of life (and they are often discussed and debatable), and on the other hand, the experience and perception of quality of life sometimes vary tremendously from one individual to another, and may even change for the same individual depending on the circumstances. Studies focusing on the disability paradox reveal the considerable gap that may exist between an external observer's perception of a disability and how it is actually experienced by the individual[56].

The considerations that prompt us to think along the lines of human betterment warrant a great deal of caution on both an individual and collective level. Asking questions about the ideal of a better future leads us to reflect on what the norm is in society, and the resulting risk of creating stigmas. Some associations such as CLHEE, which lobbies for greater equality and emancipation for people with disabilities, are helping to focus this issue back on society by challenging compassionate approaches that still contain the intention of "normalising" people with disabilities, rather than "normalising" society by embracing diversity.[57]

After examining the practices associated with reproductive medicine in today's world, it would appear that the term eugenics is inappropriate for describing the ethical issues involved.
Nonetheless, the prospect of selecting future individuals, and accepting or refusing disability, and the ensuing risk of standardisation justify the need for ongoing oversight of the ethical issues and also call for society to take an in-depth look at the more general question of tomorrow's human being[58].

[55] Canguilhem G. (1966). *The Normal and the Pathological*, Presses Universitaires de France, coll. Quadrige, 232 p.
[56] Albrecht G.L., Devlieger P.J. (1999). *The disability paradox: high quality of life against all odds*, Soc. Sci. Med., 48, 977-988. https://www.sciencedirect.com/science/article/pii/S0277953698004110?via%3Dihub
[57] On this particular subject, listen to the Cours de l'Histoire programme (France Culture) as part of a special week on the history of disability:
"Surviving is not enough. Disability: the struggle for equality" https://www.franceculture.fr/emissions/le-cours-de-lhistoire/handicap-une-histoire-44-survivre-ne-suffit-pas-handicap-les-luttes-pour-legalite
[58] This is line with the observation made by Ulrich Beck in *The Risk Society* (1986): "*The recourse to scientific results for the socially binding definition of truth is becoming more and more necessary, but at the same time less and less sufficient*."

III - TOMORROW: DO WE NEED TO BE ON OUR GUARD ABOUT FUTURE MEDICAL PRACTICES LEADING TO EUGENIC ABUSES?

III-1 GENOMICS - HIGH-THROUGHPUT SEQUENCING

As mentioned in the first part of this opinion, eugenics was inspired by breeding practices with the hope of replicating the methods used to improve animal varieties for the human species.

Such zootechnical processes have since changed considerably. Genomic selection is currently the most highly developed process in animal breeding. As indicated by Didier Boichard[59]: "*The genomic selection method is based on assessing breeding candidates using molecular markers covering the genome. Since 2009, the technique has undergone spectacular development in cattle and is gradually spreading to other livestock and crop species. It is based on reference populations whose performance has been estimated and whose genotypes have been determined. Based on these data, new breeding candidates are selected according to their genotype using predictive models*."

Given the recent extraordinary development of large-scale genome analysis technologies, could the upsurge in new zootechnical processes run the risk of awakening old eugenic dreams?

These new approaches to analysing genomes have paved the way to major breakthroughs in identifying many diseases. Combined with advances in statistical analysis techniques, these approaches have also opened up other avenues[60]. The *Human Genome* project launched in the 2000s referenced human genetic variations. In association with the results from other programmes, such as the international *HapMap* project and the *1000 Genomes* project, the results obtained have established correlations between combinations of genetic variations and numerous phenotypic traits, including height and obesity, as well as correlations with complex disorders like schizophrenia and autism[61], or with faculties such as empathy[62]. Finally, the use of artificial intelligence with an algorithm programmed to analyse DNA sequences and especially to predict the activity of certain DNA regions now heralds the prospect of predicting how variations may modify the expression of a combination of genes[63].

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[59] Genetics symposium of the Académie des Sciences (2016), Pathways in genetics - 150 years after Mendel - Symposium from 11 to 13 September 2016 - Programme (academie-sciences.fr)

[60] *Pour la Science*, 18 February 2021: https://www.pourlascience.fr/sd/genetique/le-projet-genome-humain-une-mine-de-decouvertes-21431.php - Original article: Gates A.J. *et al.* (2021). *A wealth of discovery built on the Human Genome Project — by the numbers*, Nature, 590, 212-215.

[61] Martin A.L. *et al.* (2019). *Predicting Polygenic Risk of Psychiatric Disorders*, Biol. Psychiatry, 86, 97-109. Watanabe K. *et al.* (2019). *A global overview of pleiotropy and genetic architecture in complex traits*, Nat. Genet. 51, 1339-1348.

[62] https://www.pasteur.fr/fr/espace-presse/documents-presse/genes-jouent-role-empathie

[63] https://theconversation.com/decrypter-notre-genome-grace-a-lintelligence-artificielle-152188

In addition, genome-wide association studies (GWAS) have shown that some of the quantitative traits that can be passed on (anatomical, cognitive and psychological) have a highly polygenic component involving tens of thousands of genetic variations[64]. When taken individually, these genetic variations have a very modest effect, but together they can present a risk for certain diseases. These studies also show that genetic variations may be common to several diseases. Genetic vulnerability to bipolar disorder has been positively correlated with genetic vulnerability to schizophrenia[64]. Similarly, there is a link between genetic vulnerability to migraines and depression. On the contrary, it has been shown that genetic vulnerability to hyperactivity is negatively correlated with vulnerability to anorexia nervosa[64]. Genetic variations that pose a risk for a given disease could therefore also be protective variations for another disease. More generally, it has been revealed that genetic variations associated with schizophrenia are more frequently found in people with an artistic background[65], which suggests that this genetic vulnerability can be a source of wealth for the individual and society in certain cases (depending on the genetic and environmental context).

However, care must be taken when interpreting these results, because while the additive accumulation of certain genetic variants seems to confer a risk, it is still difficult to understand how that risk is transmitted, and this does not rule out the influence that other factors, particularly environmental factors, may have on expressing the risk. Genetic vulnerability does not mean that there is a cause-effect link, but only that there is a specific susceptibility to a risk. For example, a person with a genetic predisposition to lung cancer will have a very low risk of developing lung cancer. On the other hand, that person's risk will increase significantly if they smoke or are exposed to passive smoking[66].

Although there are genetic variations with a strong impact on certain diseases, all these examples show that the genetic architecture is wide-ranging and complex in the vast majority of cases. Therefore, there is no way to eliminate high-risk variants without affecting this complex architecture. Predisposition to polygenic diseases often involves a high number of genes, most of which have not been identified. Even when they are identified, the presence of one of these predisposition genes only has relative value in establishing the risk, because it fails to take account of the role played by the other genes. In other words, **predicting the onset of a polygenic disease by studying predisposition genes has not yet taken hold in France**.

When combined with the increased accessibility of human genome sequencing as offered today by such private companies as 23andMe[67], these results carry the risk of encouraging an unabated rise in the number of requests for selecting embryos, no longer to screen for severe diseases as with prenatal testing and preimplantation genetic diagnosis, but to fuel the fantasy of "manufacturing" the perfect child by choosing traits that are currently dictated by the random expression of genetic combinations (eye colour, height, etc.).

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[64] Brainstorm Consortium (2018). *Analysis of shared heritability in common disorders of the brain*, Science, 360 (6395), eaap8757.
[65] Keller M.C., Visscher P.M. (2015). *Genetic variation links creativity to psychiatric disorders*, Nat. Neurosci., 18, 928-929.
[66] https://www.caducee.net/actualite-medicale/178/tabagisme-passif-et-cancer-du-poumon-mise-en-evidence-d-une-susceptibilite-genetique.html.
[67] https://www.23andme.com/en-int/

The CCNE stresses the importance of governing human genome sequencing and providing support in light of the ease in gaining access to such activities. The CCNE emphasises the need to "*provide the general population with better information and insights from researchers and clinicians on what genomic data represent." On the same subject, the CCNE highlights the importance of "quality care delivered by specialised staff who are aware of the latest advances in genomic knowledge*."[68]
Given the difficulty in creating a framework to govern such activities in the face of private sequencing services and initiatives, the necessary educational resources must be provided to allow the population to acquire the required knowledge. Everyone should have access to genomic data in their full complexity, otherwise dumbing down the information may perpetuate fantasies and ideologies.
In addition, access to genomic data can be a valuable asset in preventive medicine when properly supervised and supported[69].

III-2- GENOMICS - GENOME EDITING

The Chinese experiment conducted by biologist Jiankui He, which led to the birth of twin girls in 2018 who had been genetically edited using the CRISPR/Cas9 technique, painted a telling picture of the vast potential for abuses of emerging genomics. Nevertheless, it was a private initiative (like Robert Klark Graham's positive eugenics initiative of creating a Nobel Prize sperm bank).
Under French law, this experiment potentially undermines the "integrity of the species" by infringing the ban on passing on modified genetic traits to offspring. It received widespread condemnation from the international scientific community, but it raises question marks about the reasons for such condemnation. Is it due to the fear of insufficient control over genetic engineering and the consequences of passing on genetically edited traits to descendants, or has it been provoked by a sense of indignation over the ethical basis for such a betterment project?

The new CRISPR/Cas9 genome-editing technology can be used to edit the genome by making targeted cuts or modifications to the DNA (insertions and substitutions) at extremely precise points chosen by the geneticist. This prospect could usher in scores of applications, such as correcting genetic diseases caused by point mutations (see CCNE Opinion 133). However, although this technique has not been fully proven to be

[68] Extract from CCNE Opinion 129: *The CCNE's contribution to the 2018-2019 review of the Bioethics Law,* (p. 63). In particular, the text highlighted the key role played by genetic counsellors.
[69] The most iconic example of prevention using genetic testing among the general population concerns mutations in the BRCA1 and BRCA2 genes in breast cancer. BRCA1 is associated with a high risk of breast cancer, which may warrant heightened scrutiny for the onset of the disease and consequently an early diagnosis to reduce the risk of severe forms developing. The search for mutations associated with monogenic diseases is authorised in France when there are prior cases in the family, typically breast cancer in a mother or aunt, but screening is not authorised when there is no previous history in the family. However, 50% of BRCA1 mutations are observed in women with a family history. The fact that screening for these mutations among the general population is not allowed unless there is a family history means that 50% of women carrying the BRCA1 gene slip through the net. They can go abroad for screening, but this is illegal. This situation is unsatisfactory, firstly because not all women have the same opportunity to use this procedure, and secondly because the results are disclosed to them without any medical support when using the services of a foreign company. These are just some of the reasons for making this genetic study available to all women who so desire, even if there are no previous cases in their family. A similar situation concerns many other diseases, particularly familial hypercholesterolaemia, certain types of cardiac arrhythmias and cardiomyopathy, Marfan syndrome, Fabry disease and malignant hyperthermia.

harmless (uncontrolled collateral effects may appear in the genome), two other recent examples raise flags about the possibility that this technology could enter widespread use for animals and humans, which leads to fears of an abuse of eugenics.

An imminent future anticipated by research and ethical discussions

Following the genetic engineering that could soon be carried out on pigs, an article published in February 2021 highlights the issue of whether the human genome should be edited to eliminate viruses. In an effort the curb a viral epidemic causing porcine reproductive and respiratory syndrome (PRRS) in the United States and thereby save producers from facing major financial losses, scientists are planning to use the CRISPR/Cas9 technology to delete the receptor in the pigs' embryonic genome that the virus uses to enter and infect cells. British company *Genus* is planning to market PRRS-resistant pigs in China and the United States as early as 2025[70].

In addition, Quebec's Science and Technology Ethics Commission published an advisory in January 2019 entitled "*Genetically Modified Babies. Ethical issues raised by the genetic modification of germ cells and embryos*". In the conclusion, the Commission's members point out that "*the possibility that humans might one day make transmissible changes to their own genome often leads to a strong reaction of disapproval. Some defend the importance of preserving the integrity of the human genome as the common heritage of humanity. Others warn of the dangers by reminding of the horrors committed in the name of eugenics in the first half of the 20th century*."

Nevertheless, the Commission has opted for a pragmatic approach by proposing an ethical framework for these potential practices: *"Canadian federal law on assisted procreation prohibits all forms of human genetic modification that may be transmissible; in other words, any genetic modification of germ cells and early embryos. However, that law may eventually be changed. In this mission statement, the Commission has adopted a pragmatic approach that consists in identifying the conditions in which germline genetic modification could be ethically justified. To carry out its analysis, the Commission developed an ethical framework based on dignity and the common good*." This is followed by 11 conditions that could ethically justify the modification of germ cells and embryos, including the safety and effectiveness of these technologies and longitudinal medical monitoring of children who have undergone genetic modification. Several recommendations have been made to fulfil these conditions[71].

These two examples once again demonstrate how the primary objective of eugenics (despite being labelled as historical) of improving the species continues to strike a chord with events in today's world. However, genomics now offers a technology that avoids individual selection by replacing it with gene selection (or modification).

[70] Regalado A (2021). *Learning from the pig epidemic*, MIT Technology Review, 124, 44-49.
[71] https://www.ethique.gouv.qc.ca/fr/publications/modification-genetique-de-la-lignee-germinale/

It seems to the CCNE that the dizzying possibilities heralded by genome editing call for the greatest caution, using legislation[72] and also relying on scientific and philosophical humility with regard to their use on the germline genome, which can be transmitted to descendants. At the same time, the CCNE welcomes and encourages all advances in these techniques for their potential therapeutic use on the genome of somatic cells, which could offer the prospect of curing or mitigating serious diseases, particularly those cases that currently lead to talk of terminating the pregnancy.

Humility as a counterweight to hubris: scientific humility

Since genetic mutations are part and parcel of an individual's very constitution, just like chromosomal variations, the question arises as to whether these mutations constitute a medical condition or a simple difference that contributes to the diversity of the human species.
In the case of so-called recessive disorders, a gene mutation only leads to the appearance of a disease in the homozygous state, i.e. when it is present in both the maternal and paternal copies of the gene. In heterozygous individuals, who are otherwise known as healthy carriers, this mutation has no deleterious effects[73]. In some cases, recessive mutations are relatively common in the population.
Several studies have shown that they could improve resistance to infectious diseases in healthy heterozygous carriers. For instance, cystic fibrosis affects one in every 2,000 to 3,000 new-born babies in the European population, and the same *CFTR* (Cystic Fibrosis Transmembrane Regulator) gene mutation is found in 66% of patients. This suggests that healthy carriers may have had an advantage in a given situation, which led to the selection of this mutation, and this could explain the reason for its high frequency in Europe (around 4% of healthy carriers). One hypothesis claims that these healthy carriers are more resistant to cholera and other types of infectious diarrhoea[74]. The same applies to sickle cell anaemia. Healthy carriers of a mutation in the β-globin[75] gene are resistant to severe forms of malaria, which explains the initially high frequency rate in at-risk areas (mainly Sub-Saharan Africa)[76].
More recently, it has been shown that a variant of the *TNFSF13B* gene leads to autoimmunity and the risk of developing multiple sclerosis. However, that variant is highly prevalent in the population and could protect against malaria[77].. Finally, variants of the

[72] In 2011, France ratified the international Oviedo Convention, which prohibits any genetic engineering from being used to change the genetic make-up of a person's descendants (https://www.coe.int/en/web/bioethics/oviedo-convention).
[73] "*Biological complexity is no more amenable to the idea that a standard genome can be defined than it is to genetic determinism. It is an illusion to believe that there is such a thing as a "normal genome" that is somehow fixed during the evolution of humans in relation to non-human primates, and which should be preserved. Taking about normal genes and mutated genes is an aberration, since all our genes, which are products of such evolution, are mutated genes by definition. There are rare or frequent mutations. We tend to speak of variants, some of which cause diseases while others do not.*" CCNE (2016). Opinion 124, Ethical discussion on the development of generic tests linked to very high-throughput sequencing of human DNA, p. 14.
[74] https://en.wikipedia.org/wiki/Cystic_fibrosis; Gabriel S.E., Brigman K.N., Koller B.H., Boucher R.C., Stutts M.J. (1994). *Cystic fibrosis heterozygote resistance to cholera toxin in the cystic fibrosis mouse model*, Science, 266 (5182), 107-109.
[75] https://www.inserm.fr/information-en-sante/dossiers-information/drepanocytose.
[76] Luzzatto L. (2012). *Sickle cell anemia and malaria*, Mediterr. J. Hematol. Infect. Dis., 4: e2012065.
[77] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5605835/

APOL1 gene causing recessive kidney disease are also protective variants against trypanosomiasis (sleeping sickness)[78].

All these examples illustrate the importance of certain recessive mutations which, in extreme epidemics, can provide resistance to a pathogen and contribute to the survival of the human species. It is important to bear in mind that changes and developments over the millennia are not only dictated by chance, but also the result of selection according to the circumstances.

Therefore, evolution's extremely long time span must be taken into account. How can we be sure that a gene is permanently useless, even if it can currently be identified as a deleterious gene[79]? This is why the CCNE is calling for the utmost humility from the scientific community in this particular area. Given the current state of knowledge, the CCNE considers that the prospect of engineering the human genome to change the genetic make-up of a person's descendants is extremely dangerous.

Humility as a counterweight to hubris: philosophical humility

While scientific humility must remain an essential part of any discussions about genome editing in any living being, since nobody can anticipate the potential consequences, philosophical humility is another key element. The philosopher Hans Jonas wrote: "*Act so that the effects of your action are compatible with the permanence of genuine human life*."[80] But how do we define what "genuine human life" actually means?
In addition, genomics is rekindling the unquenchable thirst for knowledge about ourselves and our destiny, but there is no way that a quest for identity can be fulfilled by reading a genome at random.
As Jean-François Mattei points out: "*Although our innate part comes from the DNA molecule, it is only a person's membership of "nature" that is expressed through their genetic heritage. Culture allows us to become much more than our biological condition alone would allow... Civilisation enables us to escape the destiny dictated by our DNA. It allows the sick to draw on a number of strengths just waiting to be awakened, namely sensitivity, willpower, memory, imagination, skill and thought. Patients' fragility can conceal inner strengths, as well as remarkable moral and intellectual forces. Culture can then bring out strength where nature had decreed weakness.*"[81]
The idea of genetically modifying part of humanity could only be entertained in countries possessing the necessary technological resources. Implementing these techniques would open up even deeper and irreversible rifts than the economic and resource-related chasms that already mercilessly divide humanity. The same risk hangs over the development of transhumanist projects.

[78] https://elifesciences.org/articles/25461
[79] Henry J-P (2019). Genetics and origin of *Homo sapiens*, Médecine/Sciences, 35, 39-45.
[80] Jonas H. (1979). The Responsibility Principle, published by Flammarion, 480 p.
[81] Hearing with Jean-François Mattei by the CCNE working group.

III-3- TRANSHUMANISM

Transhumanism is defined as an international cultural and intellectual movement that advocates the use of science and technology to enhance the human condition, particularly by increasing human beings' physical and mental capacities.
The concept of "augmented humanity" is admittedly entering the mainstream and includes the use of psychostimulants to boost cognitive abilities[82], as well as more invasive devices designed to increase physical capabilities.
It is worth remembering that transhumanism is not the culmination of recent and always converging lines of thought. In this sense, a unified definition of this movement appears to be out of reach. They tend to be families of thought that are deeply rooted in humanity's long history and given new momentum in every era by religious and secular thinkers, sharing questions about immortality, man's place in a social system and ultimately his destiny in the universe.
The term "transhumanism" was first used by Julian Huxley (the first Director-General of UNESCO), who defined a "transhuman" as a man who transcends himself to create a new species that is more capable of fulfilling its destiny. Until the 1980s, transcendence was more a matter of education, self-improvement, concern for others and the gradual social improvement of societies.
From that time onwards, the libertarian spirit of Californian society, disruptive scientific and technological breakthroughs and the financial power of major technology and IT companies became the driving forces behind this quest, which is epitomised by Max More and Nick Bostrom, founders of the *World Transhumanist Association* (which became *Humanity* + in 2008).
In 1998, the "Transhumanist Declaration" was published, which has since become the benchmark for defining the main directions of the transhumanist movement. Nevertheless, strong personalities and their invariably extreme aspirations complicate the process of achieving a unified and coherent view of transhumanism.

According to Jean-François Mattei: "*The transhumanist ideology is taking the place of classic eugenics, with its bad reputation, in a new guise. The aim is the same, i.e. enhance human physical and mental performance using new converging technologies (nanotechnology, biotechnology, information technology and cognitive science).*" However, the association between eugenics and transhumanism has been refuted by the French transhumanist association *Technoprog* on the grounds that it aims to "cast aspersions" about transhumanist projects, not all of which match their sometimes caricatured image.
Marc Roux, President of the French Transhumanist Association, believes that techno-progressive goals can be developed in line with humanist values and that they are compatible with social equality, which provides new opportunities for making better health and longevity available to the widest possible audience[83], which is the main objective of techno-progressives[84].

[82] Goffette J. (2020). Augmented humanity and technological vulnerability to the self-intimate, in Vulnerability in the technological world: Ethical issues, ed. Cooreman-Guittin T., Thiel M-J., Presses Universitaires de Strasbourg, 270 p.
[83] https://transhumanistes.com/transhumanisme-pas-un-eugenisme-liberal
[84] Techno-progressives put forward a moderate vision of historical transhumanism in search of immortality.

Furthermore, the objective of improving the species in this case differs from eugenics, insofar as the improvement is not passed onto descendants and must be replicated for each new generation.
The fact remains that the human vision shaped by transhumanism raises ethical questions that, once again, should not be played down or caricatured as eugenics.

Eliminating chance and uncertainty: a threat to diversity

The advent of transhumanist projects reflects a shift, as observed by philosopher Ali Benmakhlouf, from the distinction between the normal and the pathological to the distinction between the normal and the optimal. But the optimal, unlike the normal and pathological, reduces diversity in favour of a performance-oriented vision or adaptation to a particular need, to the detriment of the many other ways of being. In their joint aim to promote betterment guided by an ideal of performance, eugenics and transhumanism constitute the same threat when it comes to preserving diversity. Eugenics (by modifying the human genome) and transhumanism (by increasing human capabilities) run the risk of becoming the norm, even if reducing diversity is not the intention of the transhumanist movement.
The matter of enhancing human, moral and intellectual capacities also deserves to be explored in greater depth. If "*human beings are the living being whose nature is to improve their nature*," as stressed by Jesuit ethicist Bruno Saintôt, they also need to question their claim to set "criteria for assessing what is appropriate". Although the issue of what is appropriate continues to be a hot topic for debate, how can we think about the "best" without this qualitative leap paralysing the time needed to develop collective thinking? Chief Rabbi Haïm Korsia draws attention to perfectibility through education, work, empathy and effort - just some of the means that have yet to be developed to overcome determinism. Since the "best" can only be achieved on the basis of the "good", additional investments in education are required to consolidate the shared values of ensuring mutual respect, participating in collective efforts and reaching out to others.

Denial of the questions of foundation and purpose

The aspect that eugenics and transhumanism have in common is that they do not only raise questions about the specific features of human life and the limits of human intervention on people at the risk of deviating from their own identity, but also the concepts of betterment and therefore the recurring matter of the good life, which underlies the ethical issue.
Eugenics, such as defined, and transhumanism, such as it appears in its most extreme projects, appear to offer a very superficial response to these fundamental questions, and it could prove dangerous to overlook the depth of these questions.
In 1919, Max Weber wrote: "*All natural scientists provide us with answers to the question: what should we do if we wish to use technology to control life? But whether we wish, or ought to control it through technology, and whether it ultimately makes any sense to do so, is something that we prefer to leave open or else take as given.*"[85]
The emergence of the transhumanist project reveals the urgent need to address the issues of substance and purpose.

[85] Weber M. (1919). The scientist and the politician, published by 10/18, 224 p. (see p. 99).

A paradoxical weakening effect

In the same way that modifying the human genome to change the genetic make-up of a person's descendants could have the perverse effect of weakening the species by neglecting functions that are presently unknown in certain genetic variations, transhumanism could also weaken those who use it by making humans subject to science and technological developments.

Return of the selection criterion

Finally, perhaps it is only on the surface that transhumanism seems to go beyond the criterion of individual selection to avoid any suspicions of eugenics. As in the case of a genetic modification that can be passed down to descendants, an economic-based selection process would inevitably take place. The risk is that not only would it accentuate the inequality between the richest and the poorest, but that a technologically enhanced species would be separate from the rest of humanity. As Maxime Crettex points out: "*According to its advocates, transhumanism should be synonymous with freedom and democracy, and it should bring greater equality between individuals by proposing to overcome the genetic lottery and biological inequalities. In reality, would this not be the hallmark of an ever more acerbic form of ultra-liberalism, where even our own bodies would need to be capitalised in a bid to provide ever more capacity and thereby make us more competitive in the future*?" [86]

Although transhumanism cannot be put in the same category as eugenics since its intended enhancements are not passed down to descendants[87], the CCNE wishes to draw attention to the potential abuses inherent in such a line of thought, which runs the risk of defining a prototype of a "better" human being based on performance criteria that reduce the many different ways of being a human, each of which (even in its most vulnerable forms) is part of a humanism that has long been inspired by the situations experienced by the most fragile among us.

[86] Crettex M. (2018). Transhumanism, dissertation, University of Geneva, 33 p. https://www.unige.ch/collegetheologie/files/2215/6751/2217/TM_Maxime_Crettex.pdf

[87] This criterion could also be discussed through the idea of an "inheritance-based" form of transmission among the most affluent classes of the population.

CONCLUSION

A semantic analysis of the word "eugenics" has shown that there are currently no practices in France that combine its intrinsic characteristics, i.e. the explicit aim of improving the human species by selecting individuals through elimination or reproductive control as part of a coercive governmental policy.

The fact remains that a number of current medical practices and issues, whether relating to reproductive medicine or the ethical dilemma of withdrawing care, raise questions about the intentions that govern these situations of choice, including the more fundamental question of what human life is. Brandishing the spectre of eugenics runs the paradoxical risk of bringing discussions to a halt and minimising the key issues that every society must address as part of a collective approach, at the risk of placing a considerable burden on individual lives, not only in great solitude but also under the subliminal pressure exerted by dominant opinions.

As far as the medicine of the future is concerned, the extraordinary development of genomics offers convincing hopes for pioneering treatments that could help resolve the ethical dilemmas associated with certain choices during the prenatal stage by allowing children to be born with serious diseases that early screening and detection could help mitigate or even cure.
On the other hand, using the same gene-editing techniques on the genome of germ cells that can be transmitted to offspring allows for the prospect of putting human betterment back on the agenda. Faced with these possibilities, **the CCNE is not only calling for caution but, even more fundamentally, for sincere humility in light of the very long, powerful and evolutionary selection process, which does not put the best individuals first, as has been thought for too long, but instead promotes living beings and their diversity.**
As Thierry Hoquet rightly points out: "*Adaptation is a patent of viability and not perfection. There are no lives that are worth more than others, there are simply lives that live.*"[88]

The most recent public debates on bioethics (2018) focused on the question of "What kind of world do we want in the future?" ». Based on the key questions covered in this opinion, we suggest that the next public debate should ask the following question: **"What kind of humanity do we want in the future?"**[89]».

[88] France Culture, episode 3 of the series covering "Darwin's On the Origin of Species".
[89] "*Despite being a supporter of eugenics, George Bernard Shaw clearly asked the question as early as 1903, suggesting that it would remain without a fully satisfactory answer, at least for Moderns who, as invariably reluctant followers of value relativism, could not consensually define an ideal of humanity: "The cry for the Superman did not begin with Nietzsche, nor will it end with his vogue. But it has always been silenced by the same question: what kind of person is this Superman to be? You ask, not for a super-apple, but for an eatable apple; not for a super-horse, but for a horse of greater draught or velocity.* ***Neither is it of any use to ask for a Superman: you must furnish a specification of the sort of man you want. Unfortunately you do not know what sort of man you want*** (Shaw, 1931, p. 218)", Taguieff, *op.cit.,* p. 92.

APPENDICES

APPENDIX 1: COMPOSITION OF THE WORKING GROUP

Mounira Amor-Guéret (rapporteur)

Jean-François Bach

Alexandra Benachi

Thomas Bourgeron

Alain Clayes

Sophie Crozier

Claude Delpuech

Pierre-Henri Duée

Anne Durandy (until December 2020)

Florence Gruat

Fabrice Gzil

Marion Muller-Colard (rapporteur)

Francis Puech (until December 2020)

Dominique Quinio

Frédéric Worms

With the support of Louise Bacquet (CCNE) and Zahira Gana (student on placement at CCNE)

In preparing this Opinion, Alexandra Benachi, Thomas Bourgeron, Claude Delpuech and Frédéric Worms were interviewed by the working group.

APPENDIX 2: PEOPLE INTERVIEWED

Ali Benmakhlouf, philosopher, University of Paris-Est Créteil

Jérôme Goffette, philosopher, Claude Bernard University Lyon 1

Haïm Korsia, Chief Rabbi of France

Anne-Sophie Lapointe (Project Leader, French Ministry for Solidarity and Health) and Alban Lapointe (Rear Admiral, Toulon)

Jean-Louis Mandel, Professor of Genetics, Honorary Professor at the Collège de France

Jérôme Massardier, gynaecologist-obstetrician, Head of Department, Hospices Civils de Lyon

Jean-François Mattei, Professor of Paediatrics and Medical Genetics, President of the French National Academy of Medicine

Marc Roux, President of the French Transhumanist Association - Technoprog

Bruno Saintôt, Jesuit, Head of the Biomedical Ethics Department at the Centre Sèvres, Paris

Didier Sicard, Professor of Medicine, Honorary President of the CCNE

APPENDIX 3: GLOSSARY

Aneuploidy : refers to the presence of an abnormal number of chromosomes in a cell.

CRISPR/Cas9: a technique known as "genetic scissors" or "molecular scissors" for making targeted modifications to the genome through cuts or other types of modifications to the DNA (insertions and substitutions) at extremely precise points chosen by the geneticist. This prospect could usher in scores of applications, such as correcting genetic diseases caused by point mutations.

Prenatal diagnosis: diagnosis carried out by means of a genetic examination of the trophoblastic cells of an at-risk foetus (at approximately 12 weeks) for an incurable genetic disease (based on existing knowledge) or a chromosomal abnormality.

Preimplantation genetic diagnosis: diagnosis carried out by means of a genetic examination on the genome of one or two cells of a human embryo obtained after in vitro fertilisation, prior to reimplantation.

Preconception carrier screening: diagnosis carried out by means of a genetic examination on blood or saliva samples taken from future parents who wish to know whether they are healthy carriers of a heterozygous mutation that is likely to pass on an autosomal recessive disease (if both parents are carriers) or an X-linked recessive disorder.

Euploid: refers to a cell with a normal number of chromosomes (46 chromosomes in humans).

Gamete: female (ovum) or male (spermatozoon) reproductive cell.

Genome: all the genetic material in a cell. The genome contains coding DNA sequences, i.e. sequences that are translated into proteins (exome), and non-coding sequences.

Heterozygous: refers to an individual with two different alleles (two different versions) of the same gene, inherited from both the mother and father. If one of the alleles con-

tains a recessive mutation, then the individual is considered to be a healthy carrier of a recessive disease.

If one of the alleles contains a dominant mutation, then the individual will develop the disease in question.

Homozygous: refers to an individual with two identical alleles of the same gene inherited from both the mother and father. If both alleles of the gene carry the same mutation causing an autosomal recessive disease, then the homozygous individual will develop the disease.

Autosomal recessive disease: an inherited disease caused by two mutations, one of which is carried by the maternal allele and the other by the paternal allele.

Autosomal dominant disorder: an inherited disease caused by the mutation of a single allele (maternal or paternal).

Here are a few websites to find out more:

- **Medical genetics**

https://www.agence-biomedecine.fr/Donner-les-cles-de-la-genetique-pour-tous-lancement-du-site-genetique-medicale?lang=fr

- **Transmission of genetic diseases**

https://www.orpha.net/orphaschool/formations/transmission/ExternData/InfoTransmission-Dreamweaver/Transmission.pdf

- **CRISPR/Cas9 molecular scissors technique**

https://news.cnrs.fr/articles/genetic-scissors-for-tailored-neuroscience-solutions

APPENDIX 4: CHANGES IN THE USE OF THE WORD "EUGENICS" IN THE CCNE'S OPINIONS

1. The CCNE's first Opinions addressing the key subjects associated with eugenics highlighted the criteria that disqualified the eugenic nature of the medical practices mentioned. For example, *Opinion 5* (1985) on the problems raised by prenatal and perinatal screening made the decision to continue a pregnancy subject to the parents' wishes, thereby ruling out the risk of "collective eugenics". Furthermore, in *Opinion 37* (1993) on screening pregnant women for Down's syndrome using blood tests, the CCNE indicated that it disapproved of any public health programmes aimed at consistently screening for Down's syndrome. *Opinion 49* (1996) on contraception for people with intellectual disabilities placed the question of generalised sterilisation for a category of the population within the field of practices that can be influenced by eugenic ideologies. Generally speaking and as explained in *Opinion 46* (1995), the CCNE warned against using genetics and predictions as a scientific endorsement of any public health policies. It also states that "*genetic tests provide information about individuals' identity and highlight their diversity, which contributes to the richness of the human race. Using this information for selection or discrimination in social and economic life, whether in the field of health policies, employment or insurance systems, would mark an extremely serious step towards undermining the principles of equal rights, dignity and solidarity between all human beings, which represent the very bedrock of our society.*" »

2. Amidst the roll-out of new genetic investigation techniques and capabilities, the CCNE took a different look at the eugenic characterisation of the newly available medical practices, starting with *Opinion 68* (2001) and particularly *Opinion 107* (2009), in which it endeavoured to identify the means likely to prevent the risks of eugenic abuses (development of best practices for prenatal screening, improving the quality of information and genetic counselling, see also *Opinion 83* in 2004 and *Opinion 97* in 2007). In *Opinion 97* in particular, the CCNE advised: "*The ethical approach to free and informed consent lies between the lack of access to available information and the obligation for access to irrelevant and unsolicited information - between the right to know and the right not to know.*" At the time, there were heightened concerns about the risk of eugenic abuses. For example, *Opinion 120* (2013) was in favour of extending prenatal screening for Down's syndrome to the general population, provided that the couples concerned were treated to a real process for expressing the choices and making informed decisions.

3. *Opinion 124* (2016) on the development of genetic testing associated with very high-throughput human DNA sequencing questioned the threats posed by the growing level of public access to screening and the risk of genetics taking over public health prevention. In *Opinion 129* (2018), following the public debate on bioethics, the CCNE came out in favour of extending preconception screening to the general population. However, it increased the number of conditions relating to consent from individuals and information sharing, and suggested that screening should only concern a range of mutations considered to be responsi-

ble for serious monogenic diseases in children or young adults, according to a deliberately restricted list to prevent any eugenic abuses. Lastly, *Opinion 133* (2019) on the ethical challenges of genome editing was clear from the outset about the ambiguity involved in these new technologies and the hope that they promise to bring to society. However, the CCNE also called for extreme caution about the inherent technical uncertainties and, even if they are resolved, the potentially eugenic nature of a medical procedure involving mutations that can be passed down to descendants. *Opinion 133* laid the foundations for this opinion.

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