

BIO

ÉTHIQUE  
ÉTATS GÉNÉRAUX



# SYNTHESIS

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REPORT OF THE FRENCH  
NATIONAL CONSULTATIVE  
ETHICS COMMITTEE

# OPINIONS

OF THE CITIZEN  
COMMITTEE



COMITE CONSULTATIF  
NATIONAL D'ETHIQUE  
POUR LES SCIENCES DE LA VIE ET DE LA SANTE

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# **The 2018 Bioethics Estates General**

## **An unprecedented citizen involvement experience in France**

The object of this document is to report on a movement of unprecedented amplitude (in France and possibly worldwide) for collective reflection on major contemporary bioethics issues. The process took the form of a public debate, held in 2018, “The Bioethics Estates General”, as provided for by French law. It was a demonstration of France's particular commitment to ethical scrutiny and to democracy in the pursuit of health.

The pace of scientific development has quickened in recent years, prompting the emergence of new challenges, raising not only complex specific issues but also ethical issues relating to the life sciences and health. Enquiring into the workings and applications of research and, more generally, into the engineering of these applications, has evolved into a major ethical challenge, as we enter into a new world which must be formulated before it can be constructed. Raising awareness on the implications of scientific research and biomedical innovation, on their uses and possible consequences, is at the very heart of what is known as bioethical reflection and the chosen object of the 2018 Bioethics Estates General.

## **I. Questions to civil society: a major challenge, an unprecedented mobilisation**

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### **1. The context**

France pioneered bioethic legislation. A specific law, named the “law on bioethics” sets out a corpus of legal rules governing medical and/or research practices affecting the human body and the embryo. The first of these laws, voted in 1988, is regularly reviewed. Since 2011, it must be revised every six years after a “public debate in the form of Estates

General” and Parliament has also tasked the National Consultative Ethics Committee (CCNE) with organising the debate.

***What does the National Consultative Ethics Committee do?***

*CCNE is an independent institution created in 1983. By law, its “mission is to publish opinions on ethical and social issues arising out of advances in biology, medicine and healthcare”. Thus, CCNE can be seen as an authentic source of reflection, thus making a contribution to the thinking of government and society as a whole. In 2011, CCNE was tasked by law to organise and stimulate public debate before the revision of the law on bioethics so that in 2018, for the first time, CCNE organised the Bioethics Estates General. The government will be introducing legislation for scrutiny and discussion by the two houses of parliament: the National Assembly and the Senate.*

*Currently presided by Professor Jean-François Delfraissy (physician and immunologist, specialising in HIV and infectious diseases, the Committee has 39 members — the “Plenary Committee”, appointed for a period of four years, once renewable. Its members are engaged in activities concerned with bioethical issues such as: medicine, philosophy, research, the law and religion. The Committee has published near on 130 opinions and reports since it was created, by a process of direct referral or self-referral.*

**2. The organisation of public debate and the thinking behind the Estates General**

CCNE saw the organisation of the 2018 Bioethics Estates General as an exercise in democracy for health and therefore invited citizens — laymen and initiated alike — and also experts, to express their opinions and hold discussions. To fulfil this new mission and to ensure its quality, CCNE created some stringent procedures: a variety of consultation channels as a guarantee of transparency and a novel critical scrutiny system provided by an “Estate General Citizen Committee”.

The various consultation channels were designed to be complementary and attempt to compensate for the bias inherent to any mode of public consultation: for civil society, information and debate took place *via* a website and in meetings organised throughout the country, while an extensive system of hearings was set up to listen to experts and organisations concerned by bioethical matters.

The Bioethics Estates General gave preference to collecting the expression of opinions, without commitment to any sampling or counting process. Bioethical issues are complex and do not call for opinions expressed simply as “for” or “against”; they must be an invitation to engage in, and reflect on, the reasons motivating a choice.

A synthesis report was drafted by CCNE following the consultation; its object was to give a factual and totally impartial account of the opinions that had been expressed by citizens<sup>1</sup>.

*As stipulated by law, the Estates General synthesis report was published on 5 June 2018 and sent to OPECST (Office parlementaire d'évaluation des choix scientifiques et technologiques – Parliamentary bureau for the evaluation of scientific and technological choices) who will be writing a report on the implementation of the previous law and evaluating CCNE's report. Other reports evaluating the 2011 bioethics law will be providing food for thought to policy makers (the report of the Agence de la biomédecine – the Biomedicine Agency report, for example) whose mission will be to delimitate the perimeter of the future law on bioethics to be subsequently voted by Parliament.*

*At the end of September 2018, CCNE will be publishing another kind of document, an Opinion — different from the synthesis report — in which it will be presenting its thoughts on what seem to be the priorities for future legislative action<sup>2</sup>.*

### **3. Themes debated**

CCNE defined nine themes for debate:

- Seven domains where scientific and technological progress was constant, some of which were already enshrined in the 2011<sup>3</sup> law or have emerged in recent years and were not always the subject of specific legislation: (1) research on human embryos and human embryonic stem cells, genetic testing and genomic medicine, (3) organ donation and transplantation, (4) the neurosciences, (5) health data, (6) artificial intelligence and robotization, (7) health and the environment.

<sup>1</sup> The report (in French only) is available on CCNE's website : <http://www.ccne-ethique.fr/>

<sup>2</sup> This opinion will be available on CCNE web site [www.ccne-ethique.fr](http://www.ccne-ethique.fr)

<sup>3</sup> See the "2011 law: main points to remember" box.

- Two themes, echoing social concerns and which may, in that respect, have evolved in recent years: procreation and end-of-life care. These two themes, which are not directly related to bioethics, were finally included by CCNE, since the Committee considered that this citizen consultation was an excellent opportunity to hear society's opinions on themes whose applications are subject to substantial regulation by French law.

#### **4. The tools**

To organise the consultation CCNE was supported by a **Steering Committee**<sup>4</sup> supervising the whole process. CCNE's Plenary Committee, composed of thirty-nine members drawn from a variety of disciplines, served in this instance as the Bioethics Estates General's "**Science Committee**". The Estates General were held **from 18 January to 30 April 2018**.

**A. The Regional Forums for Ethical Reflection (*Espaces de réflexion éthique régionaux* - ERER) initiated regional gatherings.** In France, the ERERs play a key role in bioethics. They are in close contact with university hospital centres and come under the responsibility of the Regional Health Agencies (*Agences Régionales de Santé* – ARS<sup>5</sup>). The ERERs' experience in public debating was of benefit for the organisation of debates in mainland France and, for the first time, in overseas territories<sup>6</sup>.

ERERs were given a great deal of latitude for the organisation of the debates but acted in close cooperation with CCNE. They defined methods and debating themes so that, while the classic format of public debate was broadly adopted, i.e. debate open to all, introduced by one or several experts to clarify and elucidate the issues under discussion, several regions chose other methods. Some gatherings were restricted to certain types of audiences, younger audiences in particular (secondary school pupils and university students), or to healthcare professionals, health-related associations, etc.

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<sup>4</sup> Its membership was: CCNE President, members and former members of CCNE, Directors of Regional Forums for Ethical Reflection (*Espaces de réflexion éthique régionaux* – ERER).

<sup>5</sup> ARSs define and implement public health policy in their respective regions.

<sup>6</sup> Guadeloupe, French Guyana, Martinique, Island of Reunion, and French Polynesia.

The ERERs organised a total of **271 events** each of which was the subject of a report to CCNE to serve as material for its synthesis report. Some **21,000 people** participated in these meetings. The most frequently addressed themes were “Procreation and Society” and “Genetic Testing and Genomic Medicine”. In fact, about half the debates discussed one of these subjects. A significant number of gatherings were also organised on subjects related to end-of-life and on the more general issue of the patient’s position within the health system.

**B. The website<sup>7</sup>.** An interactive website gave a wider audience the opportunity of expressing itself. Each of the 9 themes chosen for consultation was the subject of several data sheets, which were an important advance contribution to further an understanding of mostly complex and technical subjects. A forum, open to all participants who had registered, gave everyone the opportunity of commenting proposals for "issues" (possible findings), on "principles" (fundamental values brought up during debate), on "points for discussion" (concrete proposals, possibilities for addressing issues raised). To launch the discussion, CCNE initially put forward 115 proposals that the website users could supplement with their own suggestions. The proposals were put to the vote and two open-ended "for" and "against" spaces were available for participants to develop "arguments". A company was given the task of acting as a moderator so that participants' statements and opinions were respectfully addressed.

Between 12 February and 30 April 2018, a total of **183,498 single visitors** logged on to the website and **29,032 people made 64,985 contributions** to the consultation. The themes that attracted the most attention were "Procreation and Society" and "End-of-life Management", representing 69% of total contributions.

**C. Hearings organised by CCNE for organisms.** CCNE contacted 400 associations and scientific institutions, as well as organisms representing philosophical or religious currents of opinion in view of giving them a hearing. Furthermore, all organisations wishing to be heard were also invited to voice their views. Their contributions, consisting in a few pages of text outlining the points they would like to have modified in the future law were systematically posted on line.

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<sup>7</sup> [www.etatsgenerauxdelabioethique.fr](http://www.etatsgenerauxdelabioethique.fr)

**One hundred fifty-four hearings** took place between 15 February and 24 May 2018, among which figured 88 associations of healthcare users and interest groups, 36 scientific or medical learned societies, 9 groups representing philosophic or religious currents of opinion and 18 major institutions.

**D. Meetings with institutional ethics committees and experts.** CCNE substantiated the consultation through meetings with scientific and medical experts, as well as members of institutional ethics committees, on various themes such as developments in genomic medicine, embryo and embryonic stem cell research, neurosciences and other subjects.

**E. The Citizen Committee.** In order to conform to the legal obligation of contributing to the Estates General by the organisation of Citizens' Conferences, with the presence of citizens selected in such a way as to represent society's diversity, CCNE chose a novel method for citizen participation. It delegated to a "Citizen Committee" the task of making a critical assessment of the Estates General. This Committee also decided to consider in more depth two of the Estates General's chosen themes: end-of-life and preconceptional genomics. It was totally independent of CCNE and was composed of 22 citizens, aged 18 and over, mirroring the diversity of French population as regards gender, age, socio-professional category and place of residence.

They met over four weekends and heard some twenty personalities they had themselves selected. They also asked CCNE representatives to respond to their queries regarding the consultation procedures. They finalised the procedure with **three "Opinions"** which they forwarded to CCNE.

**F. The mediator.** So that citizens could be sure of being able to file a complaint throughout the process, CCNE made provisions for an independent mediator. Complaints ranged from events occurring regionally, online consultation and CCNE hearings. Monsieur Louis Schweitzer, a distinguished figure, known to the French public for his commitment to combating discrimination and defending equality responded to **152 complaints** by means of a weekly newsletter.

**G. Communications.** For timeliness and for budgetary reasons, the communications strategy mainly focused on traditional media (printed press, audiovisual, etc.), social networks and institutional support. Educational sessions were organised to sensitise the media to the themes covered by the Estates General and groups of professionals (physicians, scientists, healthcare professionals, etc.) were asked for their assistance.

## 5. The timeline

**18 January: press conference for the launch of the Bioethics Estates General**

10 and 11 February: first Citizen Committee weekend

12 February: on line consultation starts

15 February: CCNE hearings begin

17 and 18 March: second Citizen Committee weekend

14 and 15 April: third Citizen Committee weekend

**30 April: end of citizen consultation (website, regional meetings)**

4 May: experts' workshop on genetic testing development and genomic medicine

15 May: experts' workshop on embryo and embryonic stem cell research

19 and 20 May: fourth Citizen Committee weekend

23 May: experts' workshop on neurosciences

24 May: last hearings

31 May: adoption of Estates General report by CCNE Plenary Committee by unanimous vote of members in attendance.

4 and 5 June: submission of Estates General report to Ministries for Health and for Research, and to President and Vice-President of OPECST

**5 June: press conference to present the synthesis report to the public**

7 June: presentation of Estates General report to OPECST members

### ***The 2011 law: salient points to be noted***

*Research projects on the embryo and embryonic stem cells are authorised by derogation provided a certain number of conditions are observed (scientific pertinence of the research project, no other alternative to arrive at stated result, etc.*

*Concerning medically assisted reproduction (MAR), the two-year cohabitation condition for partners and common-law spouses is deleted. MAR technology is still the preserve of infertile heterosexual couples. Oocyte vitrification is authorised. Gamete donors no longer need to have already procreated before donation.*

*Pregnant women are informed and given the opportunity of testing in order to generalise prenatal diagnosis.*

*From 2011 onwards, the revision process for laws on bioethics is to include a prior public debate (Estates General) to be organised by CCNE and must take place within a seven-year deadline.*

## **II. The main lessons**

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**Research on the embryo and human embryonic stem cells (HESC):** although this theme initially gave rise to divergent positions —participants disagreed on the embryo's status and, more generally, on the legitimacy research on the embryo — most participants agreed that there was a need to legislate on such activities. Despite this consensus, criteria currently recognised by law to authorise such research<sup>8</sup> (there must not be any alternative to using embryos or HESC) was the subject of protracted discussion. While some were inclined to defend the thesis that adult stem cells, in particular those reprogrammed into pluripotent stem cells (iPS) or cord blood stem cells are indisputable alternatives for the use of embryos or HESCs, be it for research or cellular therapy, the learned societies pointed out that iPS cells are not, as yet, reliable alternative solutions. In view of the considerable potential for misuse (creation of embryos using gametes; gamete differentiation from stem cells, reproductive "cloning",

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<sup>8</sup> French law regulates research on embryos and embryonic stem cells. It requires prior authorisation, after verification of scientific pertinence, medical purpose, needfulness and compliance with ethical principles.

and more), participants agreed that there must be strict legal limits. Requests for clarification of the law — made only in the hearings of learned societies — were only briefly, if at all, discussed by civil society.

**Genetic tests and genomic medicine:** it was emphasised that there was a need for more information on what genetics tests are, or are not, on what they can do and, more generally on the emergence of genomic medicine. There is still, however, some conflict within society between the fear of eugenic developments and the wish to attenuate suffering, between the use or possible abuse of an extension of medical screening and its recognised or expected benefits. Possible future amendments to the law on bioethics and more generally to the body of health-related legislation were mainly suggested by experts in these fields who proposed in particular: the extension of some genetic diagnostic testing, such as the preimplantation genetic diagnosis (PGD) to include screening for aneuploidy or access to genetic characteristics *post mortem*. There is an incipient debate between scientists on the subject of extending preconceptional screening. Several other courses of action were mentioned as desirable: reinforcing public health policies on disablement, ensuring equality of access to healthcare throughout French territory, making secure personal data (genomic data in particular).

**Organ donation and transplantation:** giving and grafting organs *per se* were not disputed during the consultation. Gratuitousness, anonymity and consent, the principles which today preside over organ harvesting in France, apparently meet with consensus. The modalities of consent, however, were the subject of discussion and the possibility of explicit consent, to replace or complement presumed consent, was mentioned several times during the consultation<sup>9</sup>. Concerning live donation, the need to secure consent from individuals was raised on a number of occasions because of the risk of pressure from families or society. The need was emphasised to provide better protection and recognition for donors by the creation of a status. As regards deceased donors, even though there is some concern about the fact that loved ones do not invariably follow the donor's wishes, everyone agreed that they should be assisted in these circumstances. On the subject of harvesting as regulated by the

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<sup>9</sup> By law, all French nationals are *de facto* presumed to be organ and tissue donors. Everyone can deny consent by registering with a national refusal register or by making it known to loved ones, orally or in writing, that consent is withheld.

"Maastricht III" protocol, there was a wish for vigilant disconnection between the decision to cease treatment and the action of harvesting organs. For recipients, the need to create the conditions for true equality of opportunity to access grafting was reaffirmed.

**Neurosciences:** on the theme of neurosciences, civil society came up with only a few concrete proposals. In effect, research is making progress, but as yet, no specifically sensitive issues affecting society has been spotlighted, so that clear lines of disagreement have not been subscribed to. As a result, references were mainly to broad principles: the worth of research in the neurosciences to provide therapeutic solutions to neurological diseases, the need to protect individual data, recognition of the brain's complexity, the importance of steering clear of any non-medical misuse of neuroscientific techniques, and the principles of social justice as they related in particular to neuroenhancement technology. For non-medical applications of the neurosciences, opinions were more divided, as regards education in particular.

**Health data:** the information deficit frequently referred to during the Bioethics Estates General as regards technical data (anonymisation, pseudonymisation, data security technology) and legal instruments could be the reason why participants did not raise some specific issues such as for example, data sharing for research. Participants mainly expressed how they felt on the subject of massive health-related data (big data) and on the impact they thought the exploitation of such data might have on their life. Three points can be noted: (i) a demand for explanation and information on the subject of how digital tools function and, therefore, on the exploitation of the acquired data; (ii) fears that the development of these digital tools could lead to an erosion of the patient-to-doctor human relationship, as well as misgivings about telemedicine and connected objects becoming the only solution on offer to cope with the deficiencies of the health services; (iii) pervasive mistrust regarding the future fate of data and the risk of it being used for reprehensible forms of exploitation. Two forceful requests were formulated: (i) that freedom of choice for all be truly enforced, in particular *via* a refoundation of the consent process, (ii) that data exploitation not become a substitute for human healthcare decisions and that safeguards be constructed to protect privacy.

**Artificial intelligence and robotization:** as regards healthcare, new technologies are full of promise, but also raise some queries, and even

anxieties that legislators and system designers must be ready to heed. Some participants felt that if too much reliance was placed on these systems, there was a risk of dehumanising the practice of medicine. Several questions emerged: how to make sure, with such complex systems, that patients gave informed consent to their use? Who would be responsible in the event of error or a malfunctioning machine? What becomes of these big data collections and where do they leave the principle of doctor-patient confidentiality? Furthermore, although such systems may be useful in areas where medical help is sparse, they should also be available to everyone so as not to create new social and territorial inequalities. Two further issues also appear to be of capital importance: doctors and nursing staff must receive training based on an analysis of their specific role and responsibility as regards the use of these tools; as to developers creating them, they must be made fully aware of the consequences of whatever options they select.

**Health and the environment:** although this theme was not the subject of much comment, the various categories of participants not only shared a broad consensus on the importance of involving environmental factors in public health policy, but also converged on including an environmental dimension in the definition of health. Moreover, the need to be informed of environmental risks and their impact on health was also expressed. Among the subjects broached in this respect were support for public research to gain a better understanding of such issues and alerting experts to be wary of any conflict of interest with the world of competitive economics.

**Procreation and society**<sup>10</sup>: while profound differences of opinion exist in civil society on the issue of Medically Assisted Reproduction (MAR) for female same-sex couples and women on their own, everyone agreed on the importance of certain points: the positive nature of a family structure, the reality of the yearning to have a child, awareness of a parent's responsibility to a child, recognition of today's diversity in family structures. Upholding the principles of unpaid gamete donation (written into the law) and, more generally, of not merchandising the human body, was also categorically supported. Reflection was also regarded as essential on access to personal origins for children born of a MAR procedure when it

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<sup>10</sup> The law authorises MAR solely for therapeutic purposes and to remedy the infertility of a living heterosexual couple of child-bearing age, or to avoid transmission of a particularly severe disease to the child or to a member of the couple. Gestational surrogacy is prohibited.

involved a third party donor<sup>11</sup>. The possibility of authorising gestational surrogacy (GS) for societal requests was massively rejected. As regards donor anonymity, there was a consensus on the fact that children should not be denied the truth about their conception and on the distinction to be made between a donor and a "father"; however the debate is ongoing as regards what information should be revealed and how it should be accessed, but a clear distinction was made between non-identifying information and revealing donor identity, which is not equivalent to removing anonymity. Reflection on modifying filiation legislation was considered for two circumstances: a female couple, since in France, the wife of the woman giving birth needs to adopt the child; and that of the creation of a French civil status for children born by GS in another country. The issue of oocyte autopreservation<sup>12</sup> was mostly raised by learned societies and healthcare professionals who expressed the hope that the practice be authorised, but regulated and not promoted.

**End-of-life care and assistance:** there was a very broad consensus on the opinion that dying in France was a harrowing event and that a lot of progress should be made and made very soon, in particular so as to achieve true territorial and social equality in the provision of palliative care and support when a life ends. It appeared that palliative care should not be restricted to the last moments in a life and that it should be on offer as soon as a severe or incurable condition was diagnosed and announced. Also agreed was that it should be intensified, or even provided in a patient's home, which would require sizeable financial resources, further training and more information to both citizens and members of the medical professions. Thus there was a convergence of opinion on the urgent need to allocate the funds required for the development of palliative care and to ensure that the Claeys-Leonetti law was properly applied and observed<sup>13</sup>. However, there is no societal consensus on assisted suicide and euthanasia<sup>14</sup>. Furthermore, healthcare professionals and learned societies participating in hearings were largely and firmly opposed to such practices. Finally, in the light of these discussions, it would seem

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<sup>11</sup> In France, when gamete donation is involved, the donor is not authorised to know the name of the beneficiary, nor is the beneficiary authorised to know the name of the donor.

<sup>12</sup> Oocyte autopreservation, or that of gametes and germinal tissue is only authorised in France in pathological situations or in the case of treatment affecting fertility. Donors who have not procreated previously are also given the opportunity of harvesting and preserving their gametes.

<sup>13</sup> The 2016 Claeys-Leonetti law, as it is named in France, states that "everyone has a right to die in peace and dignity". It therefore calls for, inter alia, the need to respect a sick person's right to access palliative and supportive care when his/her condition requires it.

<sup>14</sup> The law does not recognise the right to either assisted suicide or euthanasia in France.

necessary to devote special attention to the most socially and physically vulnerable among us, whose wishes and consent are not always respected.

### **III – Lessons to be drawn**

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Acting for the first time as an "operator", tasked with organising and fostering public debate prior to the revision of a future law on bioethics, CCNE considers that there was momentous response and that mostly a spirit prevailed of willingness to listen and have respect for divergent and well-argued opinions. The outcome of this consultation is copious and constitutes a "collective property" to be shared first of all with French society as a whole. It also has the potential to enrich further reflection on the part of parliamentarians, the scientific and medical community and CCNE itself.

#### **1. Public debate supported by a diversity of tools for consultation**

Several tools, individual and collective, for facilitating debate, consultation, information and education were brought into play. Nevertheless, the conclusion should not be drawn that such a plurality of expression can provide a true representation of public opinion. As is frequently the case in this type of exercise, those who "know", those who have already had occasion to reflect on these complex subjects, and those who "militate" for a cause, are the ones who are most likely to express themselves spontaneously. The frequency of pronouncements in favour of this or the other development is not, in itself, an indication that they are representative of the French population.

The exercise gave rise to a certain number of difficulties which cannot be ignored. The major part of regional discussions took place in a climate of tolerance and serenity, but this was not always true, in particular during debates on so-called "societal" issues, when exchanges sometimes left little latitude for doubt, for query or for nuance, and therefore for listening to other points of view. Modes of online expression of opinion were also the subject of some criticism, such as: (i) difficulty in accessing the

website; (ii) the sometimes imprecise formulation for "findings and challenges"; (iii) moderation which some people considered insufficient; (iv) the actual definition of certain expressions which was not sufficiently acceptable to all parties.

CCNE considers however, that despite these few setbacks, the chosen method was fruitful. Thanks to the precautions taken during the debates organised by the EREs, purely "militant" expressions of opinion were not the only ones to be heard, even though it is clear that they too need to be taken on board. Moreover, the opportunity of conducting a public debate without aiming for a consensus and of reaching out to meet citizens (on their home ground for instance) contributed a great deal to the expression of a plurality of standpoints, as did also the workshops for a limited number of participants (targeting a profession or an age-group). Such encounters revealed that standpoints may vary with age or gender. Finally, hearings, which were numerous and diverse in nature, served not so much as fields of debate, but rather as a time for clarification and elucidation by the organisations who had accepted the invitation.

At this point, several findings should be emphasised:

- The significant role played by the younger generations in regional debates, varying with the themes under discussion, thanks to efforts on the part of EREs;
- The difficulty of including the less aware and the more vulnerable members of the population in the consultations;
- Finally, CCNE found that its operations were "modified", but emerges from this consultation "enriched" by reflection during this process and also convinced that such mobilisation henceforth constitutes an obligation to consolidate sustainably national and regional debate on bioethical subjects.

## **2. Points of convergence, divergence and tension**

In addition to opinions expressed in the context of the Bioethics Estates General, CCNE observed some examples of consensus, divergence and other signs of stress.

a) **There was only scant discussion on several major subjects** during the consultation, for reasons which will need to be examined. Among others, these subjects were: blood donation, the amount of attention the

healthcare system devotes to addiction, disablement, access to costly therapeutic advances, relations with the healthcare industry and, to a lesser extent, the "Health and Environment" and "Neurosciences" themes. This finding is an encouragement to consider more effective integration of these subjects into public debate and bioethics reflection in the future.

b) During the process of dealing separately with nine themes, substantial interconnections between some of them were obvious, for example genetic testing and genomic medicine with health data. But what was implicitly evidenced and can be described as a "**transformation of the heart of bioethic debate**", is a new objectification of the human body to which, for instance, the genome and health data are added to traditional corporeal characteristics.

As the Estates General progressed, there was also the confirmation of a change of view in the minds of citizens on the very **concept of medical progress**. Although medical and scientific innovation is at the heart of bioethics, queries and even disquiet seem to be emerging about the motivations of physicians and scientists and on the actual concept of progress for humans and human beings. This trend is an encouragement to pursue —in a climate of mutual trust — this bioethic interchange.

c) All that CCNE read and heard highlights the **essential need for information** which is of concern not only to the citizens who expressed it, but also to healthcare professionals. Apprehension of the technical content of the matters under discussion was only partial which may have hindered a full understanding of the issues. The need for information on the law dated 2 February 2016 creating new rights for patients and the terminally ill (the so-called "Claeys-Leonetti" law) is a pertinent example.

d) Several themes listed for discussion by Bioethics Estates General broached **the subject of research**, of its plurality of intent, since it aims to increase the store of fundamental knowledge but also seeks to fill gaps in diagnosis, therapies and the understanding of diseases. And yet, the support of society — or at least the support of those who expressed their views — in favour of the principle of research depended greatly on the subject of that research.

### **3. Where humanity fits in to the healthcare system: a concern revealed by the Bioethics Estates General**

All that CCNE read and heard in the Bioethics Estates General raises the question of **what society expects from the healthcare system and from medicine**. Despite considerable progress in medical knowledge and practices, the utopian objectives of "faultless" health and life "without risk" are singled out. Furthermore, the need to take into account a degree of vulnerability and support for vulnerable people was clearly stated, in itself a reminder of the medical duties of care and assistance.

Beyond the need for information and this reshaping of bioethic reflection, **the role of humanity at the heart of the healthcare system** was stated repeatedly, although this theme was not initially planned for inclusion. This concern and expression of need by citizens are evidence of what will probably become a crucial point of governance in tomorrow's hospitals: where do citizens — users or potential users — stand in relation to management and members of the medical and nursing professions.

a) Most importantly, as participants stated, **healthcare is not just technology**. Artificial intelligence, in particular, must not dehumanise the practice of medicine. Medical care imbued with empathy, with "benevolence" giving priority to the singular relationship between patient and healthcarer, was demanded by all. Similarly, teaching empathy and ethics to doctors was, for instance, seen as essential if healthcare providers and those they care for are to build up a trustful relationship. Procedure — which is a necessity in order to standardise medical decision — must not obliterate the time required for the dialogue enabling the singularity of the road to health.

b) **Fears that health data could be used for fraudulent or improper purposes** were also expressed (with reference to insurance companies, banks, IT security — "biohackers" — and certain governments whose laws are less protective of individual liberties). Participants pointed out that there was a need for vigilance so as to be certain that the use made of personal health data had been submitted to the patient for informed consent, and that the logic of insurance and solidarity with the social contract was not breached. Allowing citizens and patients to be "the

masters of their own data" and know what it would be used for, implies that they are also given the opportunity of taking a critical look at the algorithms, so as to evolve towards "algorithmic democracy".

Focusing more specifically on the connection between personal data and research, several public debates demonstrated the need to find a happy medium between a system for the protection of personal data and the possibility of conducting useful research for the community, even though the contribution of such data to the research is indisputable. This finding is allied to the new concept of so-called "reverse" medicine, addressing not so much the patient as the "future" patient, based on recent technology and addressing citizens in the context of preventive medicine.

The dividing line between care provider/patient dependence using a "machine" and preserving personalised medicine seems tenuous. There is palpable fear that "the machine" (referring to telemedicine or robotization...) will become a substitute for human relationships (in EHPADs<sup>15</sup>, in particular, or where doctors are few and far between). Many people are worried that such technical and scientific developments could intensify **inequalities in territorial access** to these new technologies (not to mention economic, social and cognitive disparities). Here again, the question arises of making users more attuned to, and better trained for, these new technologies.

c) Attention was specially drawn to **issues inherent to respecting differences, in particular differences generated by marginality, precariousness and poverty**, which are the cause of exclusion from the health system at a time when such situations are on the increase. The principles of equity and equality of access to healthcare are not sufficiently adhered to for people who are in precarious circumstances or on the way to becoming so. CCNE has very often pointed out that there is a need to address shortcomings in taking care of vulnerable people and those whose way of life is jeopardized by age, ill health or simply by being open to discrimination in the healthcare they receive: the severely disabled or severely dependent, those whose environment is highly precarious, migrants included.

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<sup>15</sup> EHPAD: (*Etablissements d'Hébergement pour Personnes Agées Dépendantes* – Residential long-term nursing homes for dependent elderly people)

**Respect for differences and personal singularities** were also mentioned, in particular as regards homosexual and intersex people.

d) As participants remarked, **access to healthcare is an essential right** for one and all; it is up to governments to guarantee that right. It is up to "democratic healthcare" to safeguard respect for this important and constantly threatened principle. The Bioethics Estates General thus affirmed that truly **democratic healthcare** involves a number of issues, prevention and educating for health first among them. Developing a prevention policy, implementing the potential of preventive medicine are essential for citizens.

Similarly, **tools for assessing the performance** of health systems should not be put to use without ethical scrutiny: this is the case of the "price per activity system" currently in use in French public hospitals. It attaches too much value and monetary importance to the logic of action whereas the system would be more humane if it privileged the logic of respect for the individual (attaching more value to ethical reflection, to deliberative processes in the making of complex decisions and to communication with patients and their loved ones). More generally speaking, there is a **need to be wary of allowing economic and efficiency considerations to predominate in the organisation of healthcare**, although they must enter into the equation. Another major issue raised during debates and hearings was education on vulnerability and fighting certain taboos. Finally, ranking the voices of the various players along the healthcare process and improving coordination between medical teams were judged to be issues of major importance to achieve democratic healthcare.

#### **4. A reaffirmation of ethical principles**

The lessons drawn from the Bioethics Estates General emphasise a number of bioethical principles widely accepted by participants: donation must remain unpaid, the human body is not property nor is it merchandise.

**Respect for each and every person's liberty and autonomy**, to be observed in particular *via* the need for information on technological developments, as described above; similarly, the availability of free and exhaustive information, apposite to technical developments and their complexity is a prior condition for consent, in whatever mode is chosen for its delivery. Autonomy also means being able to "keep control" over, for

instance, personal health data and handing back to individuals authority over their own data, failing which there would be a loss of liberty to make suitable choices when the need arose.

The second finding that emerges from the Bioethics Estates General puts emphasis on the social dimension of health: as participants have reminded us "we are interactional beings" and this **human relationship** is claimed, first and foremost, as part of the physician's duty of **supportive care**. What is meant by supportive care from a physician? This may be described as being ready to hear what the patient has to say and respecting the patient's choice. It is also the personal journey which may englobe the drafting of advance directives, designating a proxy or trusted person, i.e. formulate with another's assistance the ultimate phase of a life. Conversely, the presence of robots is an illusion standing in for a human relationship and can never be a remedy for solitude or lack of emotional attachments.

A third point to remember is that today's society is predominantly **respectful of the right to be different and the need to protect its weakest and most vulnerable members**. A fair balance seems to have been struck between assertion of autonomy and the need for collective solidarity, in particular for vulnerable people.

Equality for access to healthcare, supportive care for disabled people, the importance of reflecting on what human dignity represents, stand out clearly as essential issues debated in the 2018 Estates General.

This French vision of bioethics is strongly rooted in France's culture, together with a health system based on solidarity.

## Conclusion

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CCNE considers that this first experience in the organisation of the Bioethics Estates General was a positive one. It served to advance the Committee's passage from a consultative and expert dimension to a mission involving the organisation of a public debate. The French exception, bound to the existence of a law on bioethics, must be seen in the light of the nation's support for the values contained in this law. Ordered by a regular review procedure, subject to nation-wide consultation, the law serves to awaken or refresh citizen interest in bioethic issues and to inspire collective reflection to define the world we would choose to live in tomorrow. The Bioethics Estates General have proved to be an experience in healthy democracy. It is now in the hands of policy makers to take account of the outcome so that democratic healthcare can become a living reality.

**For more information:**

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