COMITÉ CONSULTATIF NATIONAL D'ÉTHIQUE
POUR LES SCIENCES DE LA VIE ET DE LA SANTÉ

March 13, 2020

COVID-19

CONTRIBUTION FROM THE FRENCH NATIONAL CONSULTATIVE ETHICS COMMITTEE

Ethical issues in the face of a pandemic

Response to the request from the Minister for Health and Solidarity

This contribution of the CCNE is not exempt from the time constraints of its purpose: it was necessary both to recognize the urgency and respond to it, without undue haste, while allowing time for the ethical process. Given the very short time frame for drafting this text, the CCNE quickly set up a working group composed of Sophie Crozier and Jean-François Delfraissy, Pierre Delmas-Goyon, Pierre-Henri Duée, Claire Hédon and Frédéric Worms, Jean-Claude Desenclos (Scientific Director of Santé Publique France), and Marie-Christine Simon (CCNE Communications Director). The draft text was then discussed in the technical section of the CCNE, during the meeting of March 12, 2020, and was transmitted to all members of the Committee. Furthermore, four hearings were held on March 6 and 7, 2020 by the working group: Mélanie Heard (Doctor of Political Science), Emmanuel Hirsch (Professor of Medical Ethics, Paris-Saclay University), Grégory Emery (Advisor to the Minister of Solidarity and Health), and Christian Vigouroux (State Councilor).

AN UNPRECEDENTED AND RAPIDLY CHANGING CONTEXT

The World Health Organization (WHO) stated that the emergence of a new coronavirus (SARS-CoV-2) in China, in early 2020, constituted **a public health emergency of international concern because of the contagiousness of this virus**. In China, where the epidemic broke out, after a period marked by a steady increase of the number of people infected, the number of cases has declined considerably following several Chinese government measures, notably lockdowns. The epidemic has since spread outside China on all continents. The WHO has since March 11 referred to a "pandemic" to describe this unprecedented and constantly evolving situation.

The first COVID-positive case was reported in France at the end of January 2020, and the first death on February 14, 2020. Since then, data published by Santé Publique France shows an increase, at first steady and then exponential, of the number of identified infections, first localized in a few areas and then in most French departments, indicating the rapid spread of the infection and the imminence of the transition to a generalized epidemic. Since early March, this has also been the case internationally and in Europe, in particular in Italy.

The government has mobilized the health system **to respond to the SARS-CoV-2 epidemic**, in three phases: detect and manage "possible cases" and "confirmed cases" and thus limit the introduction of the virus in France (phase 1); as soon as the spread takes hold slow it through an appropriate containment strategy[1] (phase 2); and, at the epidemic stage (phase 3, active circulation of the virus), **switch from a detection and individual care approach to collective action**, which requires the full mobilization of the health system in all its components, with hospital treatment for severe and serious forms and community-based practice for the most benign forms, which account for over 90% of cases, and with medical and social care establishments and pharmacies. The situation faced by the many countries affected, particularly China, therefore requires **preparation to deal with a scenario of an increasing number of severe cases**, including in its ethical aspects, even though it is difficult to determine the precise characteristics of a possible epidemic due to this new virus, given that its severity (case fatality rate and proportion of clinical forms requiring intensive care)[2], dynamics and duration[3] are at this stage unknown.

With this in mind, t**he Minister of Solidarity and Health asked the National Consultative Ethics Committee** at the end of February 2020 for its opinion about the "**Ethical Issues in the Management of Patients with COVID-19** and **Binding Public Health Measures that could**

[1] Through the isolation and management of confirmed patients in health care institutions with COVID-19 care services, active contact tracing, and quarantine at home for 14 days.

2 Comparatively, according to Santé Publique France, seasonal influenza affects several million people in France, resulting in a mortality of a few thousand people (0.1%), whereas a vaccine is available every year. In the case of COVID-19, in contrast, no vaccine or treatment has been developed, and the lethality of the virus is, according to initial data, greater than that of the seasonal influenza virus (around 1%).

[3] The only possible modeling is based on epidemic dynamics in China. It tends to indicate a duration of 2 to 3 months, even if data should be analyzed carefully in view of the different factors influencing it (population, health care system, patient management, government measures, evolution of scientific knowledge ...).

be taken in the context of the fight against the epidemic."

One of the major ethical challenges in this situation, with the transition to the epidemic and collective phase, is to **engage society as a whole in a real and effective approach of responsibility and solidarity**, because the fight against an epidemic must be a concern for everyone, not just experts and medical professionals. **In 2009, the CCNE published its Opinion 106** entitled "Ethical issues raised by a possible influenza pandemic" in which it reminded the ethical principles implemented, not to "[...] seek to make an ethical case for the essential decisions that the authorities will be required to take. Our purpose is to provide food for thought [...]", knowing that it is inevitable that some of these decisions will result in misunderstanding, dissatisfaction or protest.

The CCNE observes that despite the mobilization of society in a process of solidarity and responsibility, expected in March 2020 to confront the epidemic, **a certain mistrust** towards experts, politicians, decision makers and sometimes health professionals has grown in a large portion of the population and cannot be ignored. The "Ėtats généraux de la bioéthique" (the "Bioethics Forum") organized by the CCNE in 2018, in partnership with the regional ethics forums (ERER), noted the current weakness in the care of persons with disabilities, the elderly or dependent[4], and those weakened by illness. A fair balance must be struck between the **need for collective solidarity**, particularly with regard to vulnerable persons, and the **affirmation of autonomy**, as well as between all the dimensions of care—medical treatment, individualized support, and justice—in suggesting that **the notion of public interest is shared** by society at large.

The moment is therefore decisive because, if the health, ethical, and democratic institutions overcome this crisis, **not only will the mistrust worsening the harm be avoided, but also confidence beyond this ordeal will be strengthened**. In this perspective, timing is crucial and urgency must be counterbalanced by drawing up an action plan, management of stages and thresholds, setting up of networks, and forecasting of the next steps.

In the context of the COVID-19 epidemic, **the CCNE is now proposing** a few ethical reflections for all actors, based on the recommendations formulated in 2009 (Opinion 106) and recalling various texts published recently, nationally or internationally.

Key documents to analyze the ethical aspects of communicable diseases
World Health Organization (2016). Guidance for Managing Ethical Issues in Infectious Disease Outbreaks.
Nuffield Council on Bioethics (2020). Research in Global Health Emergencies: Ethical Issues.
REACTing (2020). ETHICAL CHARTER - Conducting Research in Situations of Emerging Infectious Disease Epidemics.
World Health Organization (2020). Ethical standards for research during public health emergencies: Distilling existing guidance to support COVID-19 R&D
CCNE Opinion 106 (2009). Ethical issues raised by a possible influenza pandemic

[4] https://www.ccne-ethique.fr/sites/default/files/publications/eg_ethique_rapportbd.pdf

SOME ETHICAL GUIDELINES FOR DECISION MAKING (CCNE OPINION - 106)

CCNE Opinion 106, published in February 2009, opened up a key issue: "whether the emergency situation caused by pandemic influenza includes the possibility of giving less precedence to certain fundamental ethical principles", noting that "The authorities are therefore confronted with the difficulty of decision making in an uncertain situation", uncertainty about the number of cases involved, the duration of the epidemic, the severity of the disease, and the effectiveness and therefore the impact in practice of the various measures on the dynamics of the epidemic, the number of hospitalizations, and mortality. Nevertheless, the decisions that will be reached, "regardless of their nature, must comply with [...] **the basic requirement on which the respect for human dignity is based**", i.e. the individual value of each person must be recognized as absolute.
Thus, this opinion pointed out that a plan to fight an epidemic "must not aggravate existing injustice", a principle of justice that can be understood in its meaning of equality (act so that each person is recognized in his or her dignity), but also fairness.

Respect for the principle of fairness being an essential condition for action in a context of limited resources, the CCNE recommended that the demand for justice understood in its meaning of equality be balanced by the need to prioritize resources. In a situation of limited resources, prioritizing patients for protection solely on the basis of their immediate or future "economic" value, i.e. their social "usefulness", is not acceptable: **a person's dignity does not depend on his or her usefulness**. Thus, in a situation of scarcity of resources, medical choices, always difficult, have to be guided by ethical reflection that takes into account respect for the dignity of persons and the principle of fairness.

The CCNE also pointed out that consideration of ethical issues "often leads to a **confrontation between principles of autonomy and the need for solidarity**", two concepts that are not exclusive, as identified in 2018 during the Bioethics Forum: "To be autonomous means to be free among other free agents, not being in opposition to them. Conversely, solidarity consists in allowing the greatest number of people to exercise their autonomy." In an epidemic of this nature, "a confused understanding of autonomy leading to rejecting treatment, the effect of which would be to facilitate the spread of the disease, would be unlikely to be acceptable by society as a whole. Autonomy would have to bow to solidarity[5].

In the case of a serious and sudden epidemic, the CCNE recommended that the authorities could take **binding measures**, "such as requisitions, confining certain categories of citizens and restricting travel".

[5] We should also add, that in the case of an epidemic and of collective decisions involving disruptions to social, personal, and professional life, supportive and follow-up measures for which innovative solutions can be proposed.

General or specific restrictions on individual freedoms must be decided and applied in accordance with the law, be in accordance with a legitimate public interest objective, be proportionate and strictly necessary to achieve that objective, without being unreasonable or discriminatory, and be defined in the light of scientific data, in particular on the effectiveness of these restrictions. Thereupon, **the CCNE mentioned the danger of extending these binding measures beyond what would be necessary to fight against the epidemic**, or because of an inappropriate conception of the precautionary principle, or as a demagogic concession. Similarly, the CCNE pointed out that all rights and freedoms that have not been specifically excluded should continue to be protected and applied.

The context, whatever it may be, cannot change fundamental ethical principles, even if an unprecedented situation like the fight against the epidemic can only compel us compel us to prioritize provisionally, but in a transparently argued manner. In the light of these principles and in the rapidly evolving context of the COVID-19 epidemic in Europe, **the CCNE proposes 10 points of attention and 4 recommendations** that could shed light on the framework for intervention by the authorities and the whole of society.

TEN POINTS OF ATTENTION PROPOSED BY THE CCNE

1. The CCNE calls for the necessary civic responsibility

The concepts of individual freedom and public interest, as well as their potential antagonism, constitute one of the major ethical issues in a plan to fight against the expansion of a pandemic. The scientific data[6], especially gathered after September 11, 2001 (terrorist attacks in the USA), indicate that citizens make trade-offs between the freedom they are willing to sacrifice and the security they might gain "in exchange". This capacity is, however, subject to their level of confidence in the authorities.
The CCNE considers, following the Bioethics Forum, that citizens' sense of responsibility is real, even if selfish behaviors are revealed on a regular basis. We must appeal to everyone to exercise individual responsibility and to explain to the public that this choice of losing a certain freedom can give more security.
The CCNE also considers that it is essential to mobilize the intermediary bodies (trade unions, nonprofit organizations, political parties, companies...) and the intermediaries closest to citizens in order to explain the measures implemented.
The right of withdrawal is provided for in Articles L. 4131-1 et seq. of the Labor Code. The worker is permitted not to take up his/her job, or to leave his or her position if he/she faces a "work situation that he or she has reasonable cause to believe presents a serious and imminent threat to life or health, as well as any defect that he or she finds in the protection systems". Its legal qualification shows that this principle is destined to come into play in some cases. Everyone therefore has a personal responsibility to exercise his or her right to

[6] Darren Davis and Brian Silver (2004). Civil liberties vs. security: public opinion in the context of the terrorist attacks on America. American of Political Science, 48: 28 https://doi.org/10.2307/1519895

withdrawal. This requires, however, the most objective assessment possible of the real danger in this specific context in which the public interest prevails.

2) The political decision-making process, based on expertise[7] and the contribution of civil society

Organized collective action to protect public health is entrusted to the State under the terms of its regalian powers. The CCNE believes that the **deliberative method** is a guarantor not only of the relevance of the policy decision to which it contributed (based on scientific expertise), but also of the confidence it will generate on the part of civil society. The aim will be to take the best possible decision, based on the best possible arguments, on the basis of available knowledge. Furthermore, before being taken this decision, which concerns the whole of society and potentially its fundamental values, should be informed by the expression of citizen opinion.

The CCNE believes that **the establishment of a joint body with the Minister of Health composed of scientific experts** from different disciplines, including the humanities and social sciences, **together with members of civil society**, particularly nonprofit organizations, able to take into account the opinions of the different categories of population living in France, especially the most vulnerable, would be a novel approach in our democracy and would help foster society's confidence in and acceptance of government action. The consistency of the decisions taken seems essential for a good understanding and acceptance of the possible binding measures or of difficult choices in health policy in this crisis situation.

3) Binding measures based on a strong legal and ethical framework and educated decision making

The CCNE extensively considered the issue of the restriction of rights in its Opinion 106: the arguments developed there remain relevant. If, in the current context, the authorities need to review the **balance between fundamental freedoms and the maintenance of law and order**, and even if public opinion might seem favorable to these security considerations, the CCNE wishes to point out that France has a legal system sufficient to **temporarily restrict** the rights of its citizens while upholding the rule of law: the Declaration of the Rights of Man and of the Citizen, the International Health Regulations, the Public Health Code, the General Code of Local and Regional Authorities, and the State of Emergency System[8]. Furthermore, the CCNE draws attention to the importance of communicating and explaining clearly and intelligibly the reasons, at a given time, for these restrictions, as well as the proportionality and the appropriate and time-limited nature of each measure that infringes the freedoms of citizens.

[7] With reference to the Health Expertise Charter

[8] Although it appears that the health crisis is not an "imminent danger resulting from serious harm to public order [or] events which, by their nature and seriousness, have the character of a public calamity".

The CCNE also emphasizes that it is important for decision makers to **keep in mind at all times the fundamental duty to explain and make binding decisions intelligible** in the context of public health emergencies, to the extent that this will influence **their acceptability**. It would, for example, be necessary to justify, based on risk assessments, a restriction of the freedom of movement from one region to another. It is essential to remember that all decisions affecting individual freedom are to protect the whole population in a spirit of solidarity.

4) Special attention to vulnerable populations

The CCNE places particular emphasis on the **issue of social inequalities in the face of risks related to the development of the epidemic**. Living and working conditions, sanitary conditions, terms and conditions of work (fixed-term contracts are less favorable than open-ended contracts), unemployment, health status, and vulnerability of poor people (14% of the population lives below the poverty line[9]) lead to specific and increased risks in this context in which precautionary measures cannot be applied in practice[10]. People who are homeless, living in precarious environments, or on the street, are in high-risk conditions. Undocumented migrants also find themselves in conditions of extreme difficulty, in consideration of their particularly limited access to the health care system.

There is therefore social inequality with regard to the risk of infection and to access to treatment. There are also real risks of stigmatization of certain social groups. **The CCNE strongly recommends that the authorities integrate fully and appropriately the issue of social inequality into their strategy,** given the risks associated with the development of the epidemic, as these crisis situations may exacerbate the difficulties encountered by these populations.

5) Transparent and accountable communication based more on society

Nowadays, communication is based on a mix comprising messages from the authorities on prophylaxis addressed to the “general public”, political communication embodied by health officials and at the highest level by the State, and communication by the health agencies supplemented by that of the experts (scientists and doctors) regularly invited to provide information on the disease. It is clear today that communication is precise (does not hide uncertainties) and cautious, despite a constantly evolving context. Moreover, the current epidemic is probably the first to be experienced worldwide in real time in the age of 24-hour news channels, social media, and live broadcasts. These resources[11] undeniably play an

[9] https://www.insee.fr/fr/statistiques/2408282

[10] The cost of a bottle of hand sanitizer is beyond the reach of people living below the poverty line.

[11] They are also likely to encourage, without any real foundation, a climate of anxiety. In this regard, we note that the use of certain words such as "patient zero", "contact tracing", and "suspected cases" maintain a climate conducive to discrimination, without providing useful elements for an effective response.

important role in informing the public and in sharing “established data” on the virus, but they also offer the possibility of identifying persons infected or suspected of being infected with COVID-19, of participating in discrimination against certain communities, and of relaying false information. We must, however, question whether, in a probably enduring context of uncertainty, the current communication tools will always be adapted in the long run. In a period when constraints weighing on individuals will be necessary from a health point of view, it is essential not to worsen the health crisis by generating a crisis of trust in society.

The current communication strategies, mostly originating from public authorities or experts, should draw on society if they are to be understood, critiqued, intellectually integrated, and then rolled out. Society can take ownership of complex ideas, communication on the implementation of binding measures, and understanding of the difficulties and dilemmas faced by decision makers, and this can give meaning to the measures taken and to their acceptability to the citizens. **The information addressed and individualized, in social, local, and professional settings, as well as personal and family, is a major gauge of trust.**

The CCNE believes that social mobilization against the epidemic should be organized on the basis of collective intelligence. **The CCNE recommends** moving from general communication to targeted communication, focusing especially on the most vulnerable and fragile (people in extreme poverty, homeless people, people with disabilities or psychiatric illnesses, migrants, prisoners …). Furthermore, it seems prudent for scientists and doctors not to make premature announcements in the media or on social media when they talk about scientific work (vaccine, treatment).

6) A requirement to be respected: the confidentiality of health data

Individuals abroad and more recently in France have chosen to publicly reveal their health status. Such situations lead to visible surges of solidarity, and empathy on social media, and can help to downplay certain experiences of home confinement, in a kind of “education through experience”. These decisions must be taken in all cases with full knowledge of the facts (malicious remarks may also be made), without social pressure. However, **the CCNE recommends that all stakeholders, individuals, caregivers, public players, and the media be reminded that there are legal texts concerning respect of the confidentiality of medical data and of the identity of those affected and that they should prevail when there is an epidemic and threat to health.**

7) An international context to be taken into account

France is tied to other countries (neighboring or not) by relations of economic and social interdependence. These relations, in a global setting, are being challenged in the context of a pandemic, where government measures tend to result in a lockdown of the country (borders closed) and the protection of nationals. In this context, the CCNE reaffirms the duties of assistance and justice: in a health crisis situation, the action of a country to expedite the end of a crisis on its territory may have adverse health effects in another country and thus be at odds with the objective of international solidarity. Thus, **the**

European scale should serve as a lever for collaboration in the development of a common policy for health crisis management, taking into account national difficulties, but allowing collective solutions. Finally, with regard to solidarity with countries with limited resources, particularly French-speaking sub-Saharan Africa, the CCNE stressed in 2009 that it "seems likely therefore that we would not live up to the duty of justice and assistance to the poorest countries when a pandemic breaks out, unless we can prepare for the event long in advance". Today, the CCNE reaffirms that solidarity towards the poorest countries is a necessity in the fight against the spread of the disease, adding that the European scale could be here a particularly powerful lever for collective action.

8) The research effort in an international framework

Mobilization of research teams, in particular at the initiative of WHO or in France within the framework of REACTing (multidisciplinary collaborative network of research institutions working on emerging infectious diseases) and Aviesan (National Alliance for Life and Health Sciences), should be highlighted and accompanied by additional funding. **The CCNE also emphasizes** that, even in emergency situations, the **research involving humans must follow ethical practices and codes of conduct**, particularly with respect to patients who are included in clinical research protocols. Human and social sciences research is also necessary, in particular with a view to integrating the needs of civil society. The international dimension of this research must consolidate public health surveillance, which has been in place for several years, so as to anticipate better the emergence of viral respiratory diseases and to provide suitable treatment. This international dimension will have also to take into account the situation of resource-limited countries.

9) The responsibility of the pharmaceutical industry

The European and particularly French pharmaceutical industry must take part in academic research efforts by making prospective drug or vaccine candidates available to medical research teams. **The CCNE also recommends** pharmaceutical companies to integrate a collective vision into their practices which, in the context of the pandemic, is expected of all relevant stakeholders and goes beyond strictly economic considerations.

10) A necessary ethical reflection for access to health care for all patients in hospitals and general practice

The emergence of the COVID-19 epidemic is unfolding at a time of stressful conditions in public hospitals. These conditions, which should not be underestimated, are linked to budgetary restrictions, bed closures, and insufficient numbers of caregivers, leading to practices that are sometimes described as "degraded". Additional and sustainable means are now an absolute necessity, particularly to cope with the current health crisis (in addition, appropriate treatments to fight against the virus are not yet available). **For severe cases**, certain technical and human means may become limiting if the epidemic crisis

worsens. Resources such as intensive care beds and their heavy equipment are already scarce and may not be sufficient if the number of serious cases is high. Therefore, when health care items cannot be provided to everyone because of their scarcity, fairness demands treatment according to the patient's needs. However, this is being challenged by justice in the social sense, which requires prioritization, sometimes under poor conditions and using criteria that are always questionable: the need for triage of patients raises a major ethical question of distributive justice, which in this case may lead to a differential treatment for patients infected with COVID-19 and those with other diseases. Those choices must always be explained and respect the principles of human dignity and fairness. It will also be necessary to be vigilant about the continuity of care for other patients.

The CCNE reiterates that the goal is to protect the entire population, even with increasing numbers of coronavirus patients. This will require not only compliance with the protection instructions for health professionals, but also measures concerning the organization of services. It should be noted in this respect that prevention and precautionary messages regarding visits to residential facilities for dependent elderly people are designed to protect the interests of particularly vulnerable people, but do not obviate the need to find innovative ways to avoid breaking intergenerational bonds over extended periods+.
Particular attention should be paid to the difficulties encountered **by health professionals of community medicine**, particularly regarding the high demand for advice and care related to COVID-19 which may be met to the detriment of other care.
The question of the link between care in general practice and in hospitals should be the subject of joint ethical reflection to define the role of each and the possible prioritization of certain patients.

The CCNE considers that health care teams need **ethical support**, which could be provided by an "**ethical support unit**", assisted by regional health agencies and guided by the experience of ethics committees, while drawing on the expertise of the clinical ethics groups of teaching hospitals.

FOUR RECOMMENDATIONS PROPOSED BY THE CCNE

The CCNE's reflections in responding to this request were largely based on one of its previously published opinions about the ethical issues raised by a possible influenza pandemic (Opinion 106). The possibility of COVID-19 epidemic is now a reality, **but the ethical principles identified in 2009 in Opinion 106 remain valid**. The CCNE is convinced that one of the major ethical challenges in this epidemic emergence is to engage **the whole of society in a process of responsibility and solidarity**. Beyond a need to improve transparency in the delivery of information, four recommendations could help citizens to take ownership of the measures implemented in the fight against the epidemic:

- An unprecedented step in the right direction for our democracy would be **the setting up of a joint body of scientific experts** from different disciplines, including the human and social sciences, **in conjunction with members of civil society**. This body would be able to take into account the opinions of the various categories of the

French population, especially the most vulnerable.

- In view of the role of ethical reflection in the management of severely ill patients and the inevitable choices to be made in reorganizing health services when managing scarce resources (intensive care beds, mechanical ventilation), the CCNE proposes the establishment of an

  "ethical support unit" to assist health professionals as closely as possible in their prioritizing of care;
- The encouragement of innovation in the solutions to be found in different areas, while always referring to a shared ethical framework (admissions policy, sharing in the organization of services, use of software tools, consistency of decisions taken, consolidation of collective intelligence);
- The rapid preparation of independent feedback and assessment from all those involved in fighting the epidemic (politicians, health professionals, scientists, citizens ...), while taking an interest in the situation of the most vulnerable populations. Recurrent health crises highlight the challenge of preparedness encompassing health, organizational, social, and ethical issues and show that feedback is indispensable.

The implementation of these recommendations will make possible another ethical dimension which is essential in times of crisis and which comes from the citizens themselves: a social pact that can be strengthened within a medical and political framework that is reliable and fair, and which presupposes respect for the rules, mutual respect, concern for oneself and also for others.