# OPINION 137

## ETHICS AND PUBLIC HEALTH


NATIONAL CONSULTATIVE ETHICS COMMITTEE FOR HEALTH AND LIFE SCIENCES

OPINION 137

OPINION 137

# ETHICS AND PUBLIC HEALTH

This Opinion was adopted unanimously by the full committee on 20 May 2021.
Version modified on 2 September 2021.

OPINION 137

CONTENTS

# SUMMARY

By publishing a comprehensive Opinion on Ethics and Public Health, the CCNE aims to define a framework that will enable our democratic society to find its bearings in the face of complex health issues that arise both in the short and medium term, such as those revealed by the Covid-19 pandemic, and in the long term. Covid-19, the cause of the pandemic, is not just a potentially serious disease: it has a collective dimension, not least because of the political choices made, in particular to try to prevent its spread. These choices have social repercussions that may clash with individual ethics, raising new ethical questions that need to be addressed specifically.

The objective of this CCNE Opinion 137 is threefold: (1) to show that all these problems can be defined by the concept of public health; (2) to show that we need to orient ourselves ethically and therefore define the general ethical benchmarks for public health choices; (3) finally, to show that the implementation of this general framework presupposes institutions and citizen participation.

Finally, all this leads us to propose, over and above the existing institutions and in conjunction with them, a General Assembly on Public Health Ethics (*États généraux pour une Éthique de la santé publique*) aimed at structuring public health in the short, medium and long term.

The aim of public health is to preserve and improve the health of the population in a given area, in all its dimensions, by putting in place a coherent set of measures and resources, mobilising multidisciplinary skills and not just health and medical skills, and constituting a public policy involving social participation.
Two directions need to be emphasised: on the one hand, health policies aimed at society, a field that is still too medical even though it is crossed by social and environmental issues and the emergence of digital technology, and which requires the diversity of groups in the general population to be taken into account; and, on the other hand, the development of individual and collective behaviour within society, with a view to preserving health, including its psychological dimension, by considering the essential role of communication and information.

Ethical benchmarks are of two types: those which have the individual as their subject and horizon, and which are based on the ethical criterion of respect for the individual, and those which are based on the notion of justice and equity in access to care, solidarity and civic participation, thus constituting a foundation of values integrating public health as a “common good”.

The key to implementing an ethical framework for public health, from the short to the long term (institutions, global context, education and teaching), is democratic institutions and citizen participation exercised on an individual or collective basis that enables the principles of democracy to be respected, in particular listening to the expectations and needs of healthcare users in the decisions that concern them, and more generally in the operation of the healthcare system.
Although there are many institutions, they are not necessarily well coordinated with each other or even approached and listened to by the public authorities. Would it

not be a good idea to think about optimising their actions, by ensuring greater co-operation between existing scientific and medical institutions in order to avoid any overlapping of responsibilities and to raise their profile?
This multiplicity of bodies and the lack of coordination between them seem to be detrimental to understanding the major role that public health should play, and make it impossible to grasp the basis and ethical aim of health policies.

If there is a tension between defining a public health policy and establishing a public health ethic, it can be a fruitful one: can the public health ethical framework not generate the implementation of new practices?
Public health requires an interaction between disciplines and professional and/or lay knowledge. The question is how to encourage health-conscious behaviour among very different social groups, both in the short and long term. Measures are needed to educate the younger generation, to take account of the international and global environmental context, and to ensure that teaching is adapted to the specific and cross-disciplinary dimension of the field.
Three distinct temporal registers, each with its own requirements, will constitute the practical application of the ethical framework: (1) crises and emergencies, which we need to anticipate and prepare for; (2) the medium term, with the establishment of balances and trade-offs in the health, economic, social and political fields in general, and the simplification of institutions for consultation, participation and decision-making; health information and citizen participation are two examples of projects to be undertaken in this context; (3) the long term, with education and teaching as part of a global public health approach, but also the organisation of the healthcare system on the basis of a public health ethic that includes, among other things, health in the workplace and the relationship between health and the environment.

Respect for public health ethics and trust in public health are two facets of the same objective: they are mutually dependent if we are to achieve the goal of public health serving the general interest. Respect for ethics, through the actions implemented, conditions the confidence of citizens in policymakers; in return, these policymakers will reinforce this respect for citizens, who are also players in the development of public health policies, present in the collective deliberation to define the actions to be taken with a view to co-constructing this common good that public health represents.
This is the meaning of the CCNE's proposal to set up the General Assembly on Public Health Ethics, in coordination with national or regional public health bodies and regional ethical think tanks.

# PREAMBLE

*The Covid-19 pandemic has brought to the fore the collective dimension of human health, known as public health, and the ethical dilemmas it can raise. Drawing up this ethical framework is all the more important because it is not just about a one-off, emergency health crisis, but also about a sustained crisis, in the medium term, as well as global issues, in the long term. The aim of this text is to show that this ethical framework for public health is also a prerequisite for progress in society.*

*The CCNE therefore proposes to address the following aspects: (1) the definition of public health, its specific aspects and its links with individual health; (2) the main aspects of public health, i.e. health policies aimed at society, but also individual and social behaviour in relation to health, without forgetting the psychological or mental dimensions, as well as information, training and communication; (3) ethical benchmarks for resolving them, which are of two kinds: general principles of bioethics and specific principles for public and collective health, centred on the general interest and justice.*

*The problems of public health involve the fundamental benchmarks of bioethics, such as freedom, dignity, consent, individual and relational support – in short, respect for the individual – in a collective context of preserving health for all, which places them in a new tension. But they also imply new ethical benchmarks, specific to public health, because they relate directly to social aspects, in particular the notions of general interest, common good, equity or questions of justice, both as a principle and as a trade-off in the event of tension between principles or choices imposed by public health.[1] (4) Finally, a series of perspectives will be put forward on specific public health issues, based on a brief review of existing institutions and mechanisms; initial practical proposals will also be put forward for putting in place the major frameworks needed to reconcile ethics, citizen participation and public health.*

[1] Examples include trade-offs within a population and between populations, the organisation of the collective healthcare system, economic, legal and social issues in general, but also in the context of citizen participation in healthcare expertise and decision-making processes, responsibility, solidarity, trust, modes of communication and deliberation.

# INTRODUCTION: A DEFINITION OF PUBLIC HEALTH

According to the WHO (1952),[2] public health is "the science and art of preventing disease, prolonging life, and improving the mental and physical health and vitality of individuals through collective action". While this definition contains a certain form of utopia, it remains precise in terms of the dimension of collective action. Above all, it paves the way for the inclusion of many fields in public health and remains relevant today, provided it is made operational:

- by considering human existence in all its dimensions (beyond the strict field of health),
- by considering health in the broadest sense of the term, not just care, but also prevention and health promotion,
- by guiding action, particularly political action, and not just in the health field in the strict sense.

**The tension between individual health and population action is already at the heart of this definition.** It confirms Paul Ricœur's paradoxical observation that the individual experience of illness and the quest for public health are in tension: "suffering is private, but health is public".[3] The adjective "public" emphasises that which relates to a community, that which is common and accessible to all (as opposed to private). Public health must take care of individual health through collective action, protecting society from the risk of "power taking over life", according to Michel Foucault.[4] As a public service, it must already respect the ethical principles of freedom, dignity and fairness. However, there may be a tension between the duty to best protect the community in which the sufferer lives and the duty to best help the sufferer.

At the time of the first lockdown, put in place on 17 March 2020 in response to the spread of the Covid-19 epidemic, the main objective was to enable each person to remain in the best possible health, and even to stay alive, by ensuring that the care system could cope with the number of serious cases to be treated in intensive care. This lockdown would not have been possible without the ability of computerisation, and digital technology in general, to provide electricity, water and food, and to maintain distance thanks to the ability to communicate so that people could continue to work, learn or seek medical care. The decision to end lockdown was based on an analysis of the capacity of intensive care units and the reduction in the number of new cases, but it was also in the general interest, in order to alleviate the considerable economic burden, as well as the social constraints weighing on the individual and on society as a whole, which were unsustainable over time.

---

[2] World Health Organization (1952). Expert Committee on Public Health Administration. Technical Report No 55, 48 pp. WHO_TRS_55_eng.pdf

[2] P. Ricoeur (1996). Les trois niveaux du jugement médical. Esprit, December 1996, 21–33.

[3] M. Marzano (2011). Foucault et la santé publique. Les Tribunes de la santé. Presses de Sciences Po, No 33, 38–43.

The health-centred approach has therefore been replaced by a broader vision of health, but also by the revelation of pre-existing vulnerabilities, linked to precariousness, personal or family situations, old age and loneliness.
**This holistic dimension of health and its medical and social determinants,** recalled in the CCNE Opinion of 20 May 2020,[5] **is at the heart of public health**. Thus medical care and public health contribute in a complementary and interactive way to the objectives of promoting and protecting the health of all, but they are different in that public health concerns the whole population or subgroups of that population, unlike medical care, which is aimed at the individual.[6]
**Public health should not be restricted to health issues, but should take into account all aspects of human existence and the environment in which we live.** And because public health is also about relationships with others, not only is the individual at the heart of the health system, as the General Assembly on Bioethics (*États généraux de la bioéthique*) (2018)[7] reminded us, but their responsibility and ability to act in the collective and in society also help in the implementation of a public health policy.

A more operational definition than the 1952 WHO definition is that proposed by Gilles Brucker and Didier Fassin: "Public health is a discipline whose boundaries have constantly shifted over the last few years: after hygiene and preventive medicine, it now encompasses all interventions concerning the health of individuals and communities, going beyond the field of medicine to include economic and social issues. If we had to venture a current definition, we would say that it is a practical approach based on health policies."[8]

Public health brings together life sciences, digital sciences and human and social sciences.[9] **This interdisciplinary approach is an integral part of public health.** The biomedical sciences enable technical advances to be made in the fight against disease. The digital sciences make it possible to understand and process information of all kinds on an individual and global scale. The human and social sciences are needed to understand people's health needs and behaviours and to guide action.[10] The factors to be taken into account are therefore very diverse: numerical, economic, geographical, demographic, legal, sociological, anthropological, psychological and behavioural; in recent years, with the One Health concept, there has been a growing awareness that

[4] CCNE (2020). Enjeux éthiques lors du dé-confinement : responsabilité, solidarité et confiance. Réponse à la saisine du Conseil scientifique Covid-19, 20 May 2020, 29 pp.

[5] J.M. Mann (1997). Medicine and public health, ethics and human rights. The Hastings Center report, 27(3), 6–13.

[7] Rapport des Etats généraux de la bioéthique 2018 | Comité Consultatif National d'Ethique (ccne-ethique.fr)

[8] G. Brucker and D. Fassin (edited by) (1989). Santé publique. Paris, Ellipses, édition marketing, 848 pp. [9] A. Desgrées du Loû (2011). Between knowledge and power: the contribution of social science research to the relevance of public health policies. In *Santé Internationale. Les enjeux de santé au Sud* edited by D. Kerouedan. Édition les presses de Science Po, Paris, 42, 523–533.

[10] The existence of a therapeutic protocol that is 100% effective is not enough to combat a disease. Patients still need to have access to the treatment, for it to be available close to home and at an affordable cost, for them to agree to take it, to comply with the dosage, for their family or friends not to be an obstacle to the treatment, and for the treatment to bring about an improvement felt by the patients.

public health must also incorporate an environmental approach, linking human health with animal health and respect for the environment.[11]

**Box 1: CCNE definition of public health**
The aim of public health is to preserve and improve the health of the population in a given area, in all its dimensions, by putting in place a coherent set of measures and resources, mobilising multidisciplinary skills, and constituting a public policy.

**However, this definition of public health cannot be separated from that of individual health,** which the WHO defined in 1946 as follows:[12] "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."
Everyone's health depends on the availability of ever more effective medical resources and on national solidarity to make costs that would be unbearable for most citizens "invisible". More generally, to improve "our" health, we also need to improve our working and living conditions, in economic, social, environmental and food terms. These dimensions are particularly important in the concept of primary healthcare,[13] or "personal medicine".[14]

Ensuring the best conditions for the biological, physical, emotional and cognitive development of children at an early age should enable them to reach their potential in terms of long-term health and socioeconomic return for society. Investing in this period also brings the hope of reducing the perpetuation of social and health inequalities from generation to generation.[15] From childhood onwards, individual health is therefore linked to interactions with others and with the environment. The exposome, a concept corresponding to the totality of external environmental risk factors (physical, chemical, biological, social, psychosocial) to which a human organism is exposed, from conception to the end of its life, takes on its full meaning here.[16]

**Health is as much a social fact as a biological one.** "A child is not born an orphan and a human being does not live isolated on a desert island, which means that any health action must take place in the context of daily life and be based on a good knowledge of the environments and living conditions, the needs and aspirations of families and communities." (Monnier et al., 1980)[17]

---

[11] See CCNE report No 125: Biodiversité et santé : nouvelles relations entre l'humanité et le vivant | Comité Consultatif National d'Ethique (ccne-ethique.fr)
[12] Constitution of the World Health Organization : Constitution (who.int)

[13] Declaration of Alma-Ata in 1978: Primary healthcare (PHC) is a health strategy based on prevention and implemented through community participation, to improve and mobilise the people and local resources available, but also to promote the dissemination of knowledge and "preventive" behaviours and attitudes within the community.
[14] This approach contrasts with the exclusively organicist approach to disease.
[15] *"Les 1000 premiers jours – là où tout commence"* report: rapport-1000-premiers-jours.pdf (solidarites-sante.gouv.fr). In addition, the work of Nobel Prize-winning economist James Heckman has shown that the return on investment is all the greater the earlier the age, while spending on health and prevention is all the lower around this age.
[16] For example, exposure to chemicals (environmental or medicinal), infectious agents, unbalanced nutrition, or psychosocial stress in the prenatal period or in the first months or years of life are all factors that have been shown to have long-term consequences on individual health.
[17] J. Monnier, JP Deschamps, J. Fabry, E. Berthet, A. Roussel, R. Senault (1980). Santé publique, santé de la communauté, Villeurbanne, Éd. Simep, 443 pp.

People's attitude to prevention is closely linked to their culture, socioeconomic level and education. Illness and death are also cultural phenomena, interpreted differently in different societies and at different times. The Covid-19 epidemic is a reminder of what has already been underlined with the HIV/AIDS epidemic: major health threats are not just "health defects", but "total facts" that shape society and institutions.

**Ethical reflection on public health should therefore be rooted in a global vision of mankind,** without taking the form of a utopia. It presupposes a precise articulation of public health and ethics, at both individual and collective levels, to respond to the problems it raises and which the pandemic in particular has highlighted.

This is the approach proposed by the French National Consultative Ethics Committee (Comité consultatif national d'éthique, CCNE), which continues or rather integrates into an overall framework elements that have already been considered in previous Opinions, in particular Opinions 57 (Technical progress, health and the model of society: the ethical dimension of collective choices, in 1998), 101 (Health, ethics and money: the ethical issues of budgetary constraints on healthcare expenditure in hospitals, in 2007), 109 (Communication of scientific and medical information, and society, in 2010), but also 127 (Health of migrants, in 2017) and 128 (Ethical issues of ageing, in 2018). This discussion was prepared by a working group, whose members are listed in Annex 1, which conducted a number of hearings listed in Annex 2.

# I. MAIN ASPECTS OF PUBLIC HEALTH

Two major directions can be highlighted: (A) "public health", understood as health policies aimed at society. To this we can add matters of trade-off within the group: prioritisation between populations (for example, according to vulnerability or responsibility), but it also refers, in the opposite direction, to (B) a construction of individual and collective behaviour in society, with a view to health, with the psychological dimension and that of communication and information.

## A. PUBLIC HEALTH POLICIES AIMED AT SOCIETY

*A field that is still too medical*

Health policies, in the traditional sense of the term, are primarily concerned with the organisation of the health system, which to date has been thought of essentially as a curative health organisation. Care and treatment are thus organised between the hospital (comprising a public sector and a private sector) and the home (primary medical care). The social sector is excluded from the organisation of the healthcare system (even though the medico-social sector is often attached to it). Some areas (e.g. psychiatry, palliative care, and even more so health promotion and health education) are the poor cousins of this organisation. It therefore suffers from a lack of an integrated, global, systemic approach to health.

**As far as prevention is concerned,** it obviously contributes to good health: preventing the onset of illness or a life-threatening accident is essential. However, we need to be vigilant about the way prevention is used in public health discourse: it must not become an endlessly repeated invocation that is satisfied with its two main practices: screening and prohibition. It needs to be seen in a broader context, particularly the political dimension.

The **issue of prediction** is becoming crucial because, particularly with genomics, digital technology and artificial intelligence, it is leading to a completely different way of looking at disease (the risk of disease) and therefore "health" policy. It is the healthy person and his "risk" that become the target before the disease. This involves a complete change of thinking that goes far beyond traditional screening (for breast or colon cancer, for example).
Public health policies will inevitably be affected.

*Digital technology at the heart of public health*

As digital technology has become central to contemporary society, it has become a key element in public health.
From a health point of view, its importance has recently been highlighted.[18] It is transforming diagnosis and treatment. It can be used for epidemiological monitoring, as was the case with Covid-19. It enables shared medical records to be created, and large-scale data to be shared and exploited for medical, pharmaceutical or genomic research, as well as for clinical use, not only consolidating the predictive approach, but also better characterising the uncertainties of knowledge. Digital technology has be-

[18] Numérique et santé : quels enjeux éthiques pour quelles régulations ? | Comité Consultatif National d'Ethique (ccne-ethique.fr).

come essential to vaccine research, as demonstrated by Covid-19, and has proved indispensable to the entire vaccination logistics chain, making it possible to control the production and distribution of billions of doses of vaccine in record time, as well as the vaccination schedules and tracking of those vaccinated. The growing role of telemedicine and tele-operations, the remarkable capabilities offered by digital technology for micro-invasive surgery, and the capabilities offered by digital technology for the education of healthcare staff are all illustrations of the importance of digital technology in public health.
Digital technology also contributes to public health in areas that are not purely medical, such as the use of digital approaches to improve lifestyle, physical activity and diet. It enables precise tracking via objects such as connected watches.
**While digital technology and artificial intelligence are making a major contribution to public health, the underlying ethical issues are nonetheless significant,** for example when it comes to personal health data, which means we need to be particularly careful about how it is used.

*Taking into account the diversity of groups in the general population*
While public health concerns the general population, it also has to make distinctions and trade-offs, and consider actions aimed at more vulnerable or fragile populations, or those in specific health situations, but which nonetheless concern the interests of all, the general interest. But how can this often necessary discrimination be established without triggering a feeling of stigmatisation in the people concerned? How can we combat inequalities and different risk factors without making people feel guilty and stigmatising them? What are the ways in which public health measures can be adopted rather than rejected?

**Public health systems, which are generally designed for a "general" population, therefore appear to be ill-suited to the most vulnerable groups.** To avoid this pitfall, it would be advisable to build systems with and for the most vulnerable people – or at least for the population we are trying to reach – on the assumption that these systems will be all the easier to reach for the rest of the population.
However, it is precisely the development and structuring of these different population groups that poses a problem.

This presupposes that such categories exist and can be mobilised by and for political action, a prerequisite that is far from being met. Sociology has long shown that a great deal of social work is needed to make a group visible and meaningful to society as a whole, and to policymakers in particular.
The question of how and why certain groups manage to be recognised and to recognise themselves, to make themselves heard and to have their specificity recognised is a crucial public health issue that ethics must absolutely take into account.

*Ethics and politics: what questions are raised?*
More generally, how can ethics be articulated with politics? **It is the issue of social justice,** in its various forms, including that of solidarity,[19] that could make the link with politics and thus build an ethical framework for public health, capable of restoring

[19] particularly solidarity with the most vulnerable people and populations, which is the very definition of a society.

more confidence in public policies. It is important to remember that public health policy aims to achieve equity between different social groups,[20]

But it is not enough to think of health policies in terms of society; it is also necessary to develop the individual and collective behaviours that, as the pandemic and lockdowns have shown, are at the heart of public health.

## B. THE CONSTRUCTION OF PUBLIC HEALTH IN SOCIETY

***Public health is not just about the society that is the object of public policy; it also owes its success to the attitudes of those who make up that society. As a result, it must also be aimed at individuals.***

The question of individual support for public health policies is crucial,[21] but should we not also be stressing a certain contradiction between public health and what the individual wants? Just as in the case of autonomy, where we quickly see that the autonomy of a person whose health is seriously impaired depends on others, individual health cannot be seen as detached from others, from the environment: *My health depends on the health of the community, the society in which I live.*

**The aim of public health is to reduce inequalities and ensure greater equity** in the provision of goods and the allocation of resources to the most vulnerable. It aims to make everyone a player in his own health and in the health of others, albeit with difficulties: how can we reconcile issues of freedom, equity and dignity? Should not a public health policy enable everyone to exercise his responsibility and express his autonomy for the benefit of the general interest? Is public health sufficiently participatory? Ultimately, are not these aims in part what help build the moral and social acceptability of public health policies?

A public health policy can quickly appear to be a restrictive, even "liberticidal" policy for the individual, in the name of an objective that they may not wish to see achieved, despite the existence of a protective aim. During the Covid-19 health crisis, limiting freedom of movement was perceived as a constraint that was sometimes difficult to accept. It is important to try to reduce this tension by setting out the facts, the possible solutions and the reasons that led to the decision: explaining can help make restrictive measures more understandable and acceptable.

The WHO definition highlights a way in which public health operates that could be described as "vertical": imposed on citizens from outside, with the injunction to achieve the set goal (to be in good health). But because the "public" dimension also refers to relationships with others, the question of **how to shape individual and collective behaviour** is raised with new acuity.

Society as a whole must be involved in a process whose effectiveness will depend on its mobilisation. To improve both disease prevention and optimal treatment, we need

[20] For example, while the elderly had been designated as the main beneficiaries of the policy to combat Covid 19 – because they are the main victims of the virus – it has recently become apparent that young people are suffering greatly from the actions taken to date, and that the policy needs to be redirected towards this other category – or at least to find a way of better articulating the policies aimed at these two categories.

[21] How can we encourage people to adhere to public health standards? How can these standards be built with the support of society as a whole and not just healthcare professionals?

to involve society as a whole. The two-way process should be ongoing, with a bottom-up input: gathering the public's perceptions of public health, taking into account the knowledge of "lay people" and "experts in the field", particularly patients' associations, so that public health is not, ultimately, the sole preserve of the "experts".

Finally, in public health, it is important to emphasise the relativity of the knowledge produced, because the dynamics of public health are not the same as those of science.[22] This also means that programmes have to be adapted to suit different areas, social groups and cultural references: the people affected by these programmes should be involved in their development to help designers make them more accessible to the target audience.

*Individual or collective resistance to public health projects*

Public health strategies can also meet with unprecedented resistance to their prospects, a phenomenon that can lead to a prevention project reaching an impasse,[23] even if it had met with everyone's approval.

A dimension of acceptability would be indissociable from any public health project, a psychological dimension,[24] as a first condition for a public health perspective to succeed. Considering this psychological dimension in relation to the acceptability of a public health project also means recognising that the most intimate issues can interfere with the collective, against the good of all, against the good of each individual, an issue at the intersection of the intimate and the collective.

**These individual resistances can spread rapidly and become collective resistances to public health objectives,** resistances which are sometimes established on the basis of individual anxieties which can become collective anxieties (e.g. resistance to vaccines), going so far as to annihilate public health action. Trust becomes distrust. The possible becomes the impossible. Because the facts on which public health proposals are based are considered to be unfounded, certainty turns to uncertainty, and even concern. Ignorance replaces knowledge to the point of refusing what is proposed and encouraging denial to take over the stage.

The experience of the health crisis is interesting in this respect. The initial certainties set out by medical and/or political authorities, often quickly contradicted by the facts, have led to increased anxiety among people and a loss of confidence, sometimes leading to distrust. A more modest and humble approach would probably have led to greater acceptance of the public health proposals, which are restrictive when they concern, for example, distancing and protection measures, vaccination, etc.

Various factors such as uncertainty, instability and the limits of knowledge can accentuate the ambivalence and tensions between the individual and the collective, to the point of increasing pre-existing divisions or leading to fractures between populations.

---

[22] As a result of its interdisciplinary nature and the changing empirical situation, public health knowledge is evolving at a radically different pace to that of its neighbouring sciences, which contribute to the richness of public health. It is therefore very difficult to imagine the transformations in public health, whereas it is easier to have an idea of what medicine, for example, will be like in the more or less near future.

[23] There are many examples, including prevention programmes on smoking, diet, alcohol, exercise, lifestyle and even speed limits.

[24] The choice of the qualifier "psychic" is intended to distinguish "psychic health" from "mental health", which refers to the specific field of mental illnesses, such as depression, schizophrenia and other specific disorders. Public mental health certainly suffers from the same resistance as any other area of public health.

*The essential role of information and communication*

In this context, information and its educational aims play an essential role, because it is thanks to them that we can communicate about public health, which ultimately amounts to building it. Should we not be asking ourselves what the nature of information is today? In 2020, in the midst of the health crisis, the WHO updated a concept known as the infodemia,[25] a deluge of information in which it is becoming impossible to find one's bearings, beliefs that spread like a virus, and fake news about epidemics.[26]

The blurring of expert opinion (are the best experts the most available?) is also part of the disinformation process. The Dunning-Kruger effect[27] was illustrated in many ways in the health crisis. The underlying question, which is fundamentally ethical, is: how can we take stock of what we do not know? Who is best placed to say so? Should public health not communicate the relativity of knowledge, the existence of limits to "knowledge", etc.? **Should public health not also take an approach to the uncertainty that is consubstantial with "health"?**[28]

What needs to be done to overcome the information confusion? Identify reliable sources of information and the tools (institutional, human, technical) that can be used to provide this information, and make crisis recovery scenarios clearer, for example in the case of a health crisis. Think about the degradation of information in its multiple dimensions and remain attentive to the diversity of sources of misinformation – in short, the epistemological vigilance of the communities concerned needs to be implemented. It is therefore necessary to maintain an empirical attitude in the face of distrust (the political stakes of overestimation) and to recognise the importance of knowledge in the current situation, without forgetting the other dimensions of democratic deliberation.

It is precisely here that an ethical principle of vital importance in public health must be asserted and upheld: the **principle of clarity and transparency**, with a genuine effort to explain both the source of the discourse (the public health player speaking) and its subject.

Yet public health discourse is very often made up of a shifting aggregate of contradictions, which highlights the need for another major principle: **the principle of complexity.** It is not easy to resolve these antinomies, which are consubstantial with the way we think about public health; they have to be accepted and explained as such in the name of the principle of clarity.

---

[25] Managing the COVID-19 infodemic: Promoting healthy behaviours and mitigating the harm from misinformation and disinformation (who.int)

[26] Information is an integral part of the pandemic. This is not just a media issue, but also a scientific one: it affects the volume of publications, in particular through the explosion in the number of preprints. This exponential growth is a measure of the investment made by the research community, but it also brings the ideal of open science into conflict with standards of scientific integrity.

[27] The Dunning-Kruger effect, or overconfidence effect, is a cognitive bias caused by experts with few qualifications in a field overestimating their skills:

Dunning–Kruger effect – Wikipedia (wikipedia.org).

[28] The current pandemic shows the place of false generalisations, in the form of sophisms, false scientistic beliefs and abusive generalisations that take on the appearance of truth and spread as pseudo-knowledge about public health. This trend is fuelling mechanisms of distrust, accompanied by the spread of fake news and rumours that can invade the social sphere, compromising public health initiatives.

Public health, particularly with digital technology, artificial intelligence and predictive tools, could revolutionise medicine by calling into question established notions which, over time, have taken on the force and weight of evidence.[29] Analysis of the social determinants of health sometimes contradicts certain received ideas.[30]

This dual relationship between public health and knowledge crystallises in a particular example relating to mental health.[31]

This is why public health initiatives also involve an ethical and political dimension, over and above medical advances and the state of healthcare systems.

[29] For example, the link between the treatment of tuberculosis and the discovery of antibiotics should not blind us to the overall effect of the social and economic development of our societies in reducing the incidence of the disease.

[30] The risk of strokes is more likely to affect people who suffer than the "white-collar" workers who manage them, as illustrated by M.G. Marmot (2004). The Status Syndrome: How Social Standing Affects Our Health and Longevity, Bloomsbury, London, 336 pp.

[31]The concepts of vulnerability and individual trajectories, derived from epidemiology and the monitoring of situations where risk factors are accumulated, are replacing traditional clinical structures, and even the DSM (Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association) item tables.

# II. ETHICAL BENCHMARKS: RESPECT FOR THE INDIVIDUAL AND JUSTICE

The main issues we have just raised **call for ethical benchmarks in two areas**.
Bioethics was initially conceived in relation to research in biology or medicine, with the individual as subject and horizon (A), and the criterion of respect for the person put forward. But simply transposing bioethics concepts to public health would be neither effective nor ethical. We will therefore discuss how these concepts can support the public health system, but also the need to build a specific framework, the overall principle of which is based on the notion of justice (B).

## A. GENERAL BENCHMARKS OF BIOETHICS: RESPECT FOR THE INDIVIDUAL AND THE ETHICS OF CARE: THEIR APPLICATION TO PUBLIC HEALTH

*Ethical benchmarks*
Ethical reflection is based not only on values and but also on the most lucid possible assessment of the benefits and risks for the individual, without omitting to consider their possible extension to the greatest number and bearing in mind that the risks are those incurred by all living organisms and not just by the human species.
These benchmarks are obviously provided for the most part by the founding values of societies, such as the guarantee and protection of human dignity, freedom and autonomy, equality and solidarity, tolerance and fraternity, justice and equity. No *a priori* hierarchy of values is possible, and only the protection of human dignity provides an ethical benchmark that cannot be surpassed, not so much for setting positive standards as for laying down prohibitions (such as the commodification of the human body or undermining the protection due to the most vulnerable).
Some of these values are shared internationally, while others have a long history in French culture.

*Are these values applicable to public health?*
Public health calls into question the ethics of healthcare practices, as well as the ethical foundations of the healthcare system. Often confronted with misunderstood performance issues, this can lead to the overmedicalisation and sometimes the commodification of the human body, or more generally to the commodification of health.
**This notion of performance may ultimately alter the collective dimension of the pact of trust**: how can we think individually and collectively about the relationship to risk and the relationship to responsibility in a process of co-construction of a healthcare system?
The notion of performance also leads to choices being made about care projects that do not necessarily meet the health needs of the population, but rather profitability objectives.
Does the ethical dimension of care conflict with the performance challenges of the healthcare system? What health policies and what health system can guarantee ethics? The fundamental dimensions in this respect include information, education, training and anticipation, etc.

It is therefore important to ensure that certain major public health tools do not cover up the subjective nature of each individual.

## B. SPECIFIC ETHICAL BENCHMARKS: FREEDOMS, EQUALITY, SOLIDARITY IN THE LIGHT OF THE COMMON GOOD, THE GENERAL INTEREST AND JUSTICE

However, it is not enough to maintain or apply the principles of bioethics in the field of public health, even though this will be necessary. In its collective dimension, this raises specific questions that call for notions of justice, common good, general interest and solidarity, with the question of inequality playing a central role. The issues at stake can be presented in terms of **three ethical questions or questions of justice in public health**: individual freedom or autonomy and collective responsibility; equal access to resources, including information; and the participation and solidarity of citizens as players in public health.

These headings will lead to the definition (part 3) of perspectives both for crises and their short-term emergencies and for the medium term and institutions in the long term.

*Freedom or individual autonomy and collective responsibility*

A first illustration of issues relating to freedom concerns the objective of respecting the autonomy of each individual while preventing as far as possible the harmful consequences of certain behaviours for himself and for others: addictions (tobacco, alcohol, drugs), dangerous driving, etc. In other words, ensuring that people have the autonomy to make their own decisions, while taking responsibility and respecting the autonomy of others.

Once again, this raises the question of coercive health policies: assuming responsibility means being aware of the risks associated with certain behaviours and making the best choices to protect your own health and that of others. However, research into tobacco or alcohol consumption, or the protection of sexual relations against the risk of HIV, has clearly shown that knowing the risk is not enough. Faced with this situation, prevention in certain areas (e.g. road accidents, drug use) is based on prohibition and punishment, rather than on making people more responsible.

However, psychosocial research into the theory of commitment has shown that taking responsibility and encouraging personal commitment can lead to changes in attitudes, and could be used more effectively to reduce this public health dilemma.

A second example concerns the ethical rule of proportionate risks, maximising beneficial effects and minimising harmful ones. In public health, this ethical rule means that both the beneficial and the adverse effects must be taken into account, both in the fields of health (physical or psychological) and in the social or economic fields. The aim is to take into account the beneficial or harmful effects on people's lives in all their dimensions, which means collecting information on all these dimensions.[32]

[32] Large cohorts such as "Constances" or "Elfe" are designed for this purpose. One difficulty is the level at which these effects are compared: one programme may have a beneficial effect on one group of people and a harmful effect on another (e.g. lockdown during the Covid-19 crisis).

*Equity in access to resources*

The CCNE also questioned the existence of benchmarks specific to public health, particularly from a population perspective.

In this respect, economics, like public health, is population-based.

Health has an impact on people's well-being. But what does public health mean for the economy? It means first and foremost thinking about the best possible allocation of scarce resources in order to: (1) achieve maximum well-being in society, a well-being that depends on health, but also on other dimensions; (2) guarantee the "efficiency" of the health system and (3) guarantee equity in health and well-being in general.

Thus economics is liberal because it wants to preserve the freedom of choice of individuals, their fundamental preferences. The economist believes that people do not make choices at random, and that deliberate choices indicate their preferences, i.e. their tastes and conceptions of the good life.[33]

We cannot assume that people do not know: there are biases, but they are not absolute. Similarly, the regulator's social choice must not be authoritarian and must be in line with society's priorities in terms of life, survival and the other dimensions of life.

However, economics can also be "paternalistic". Paternalism is justified when agents have genuine flaws in their rationality, in their understanding of what is at stake, in order to reduce behaviour that is a source of negative externalities, i.e. negative consequences in terms of well-being, health or costs for others, and to increase behaviour that is a source of positive externalities, i.e. positive consequences in terms of well-being, health or economic benefits for others. The existence of these externalities therefore justifies the fact that the individual may be thwarted in his initial decision.

For health economics, guaranteeing public health also means guaranteeing a fair distribution of the resources of the health system, of the burden of financing all the care in the basket offered by the public system and of the results in terms of health. First and foremost, it is a question of **guaranteeing horizontal equity in the consumption of care and vertical equity in the financing of care**. The principle of horizontal equity in the use of care requires equal treatment: to each according to his needs.

This principle therefore prohibits any inequality in the use of healthcare for the same need for care, for example, according to standard of living or place of residence. Providing care to those who are suffering is a basic respect for human dignity, and fair access to care for all is an essential element in reducing health inequalities.

More generally, everyone should be **guaranteed access to a state of health that enables them to lead their lives according to their own ideas of the good life**, whatever their standard of living or where they live.

The principle of vertical equity in health funding is different, as it requires funding to increase with income, irrespective of people's need for care and their use of the system. This is the basis of solidarity in the healthcare system. This principle requires,

[33] If a smoker derives more satisfaction from smoking than from not smoking, and public health upsets him, then his well-being is diminished. We therefore need sound justification for implementing an anti-smoking policy aimed at preventing him from smoking, by highlighting the costs to himself, which he would be unable to consider in an informed way, and the health consequences and cost to society.

first, that the amount[34] paid by a person for their care should be independent of their level of care use. The aim is to ensure that people's health does not become a source of excessive out-of-pocket expenses, or an increase in inequalities in living standards, after contributing to the cost of healthcare.[35] In particular, the aim is to **ensure that healthcare funding is not a barrier to access to care**. The financing of a healthcare system will therefore be considered inequitable when it does not increase with income or when it increases with the need for and use of care.[36]

The economic legitimacy of activities aimed at improving public health necessarily involves ethical reflection which, in the words of Amartya Sen, must "reincorporate economics into moral science".[37] Systematic differences in health status between social groups of a given age and gender can therefore be described as health inequalities or social inequalities in health. However, it can be argued that not all health inequalities are inequitable: only those linked to circumstances beyond the control of individuals are inequitable: this is known as inequality of opportunity in health.
By way of illustration, the strategy chosen to combat Covid-19 is effective in curbing the spread of the virus, but is simultaneously generating an increase in health inequalities, a major economic crisis and "human capital" risks. Managing a pandemic inevitably involves a trade-off between health risks, socioeconomic risks and freedom.

A final example highlights a specific ethical tension when it comes to giving everyone the same access to information, prevention or health services, in the knowledge that not everyone has the same initial resources to take advantage of them. What has become of the principles of equality, justice and fairness? Research into health inequalities has clearly shown that health promotion programmes can exacerbate health inequalities: for example, access to green spaces and physical activity, or to a varied diet, is influenced by determinants such as education, income, gender, place of living and work. Universal programmes can benefit people who are already in a favourable situation and fail to improve the situation of others who are in a less favourable situation, widening the health gap in return. An intervention offered to all (universal) can help the whole population and promote well-being overall, but with interventions that do not reach those who need more support and are harder to reach. These observations have led to the **notion of proportionate universalism**: "Focusing solely on the most disadvantaged will not reduce health inequalities sufficiently. To reduce the steepness of the social gradient in health, actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage."[38]

*Involvement and solidarity of citizens, players in public health*
Finally, there is a third series of specific ethical benchmarks which correspond to the very nature of public health. This is because it is based not just on principles applied to the "population", but on collective behaviour itself.

---

[34] This amount is taken to mean all contributions towards the cost of care, whether through contributions to the public health insurance system (via social security contributions and taxes), premiums and contributions paid for supplementary insurance or out-of-pocket payments made directly.

[35] This principle also requires that all contributions to the payment of care by individuals should be based on their ability to pay (in particular their income), in accordance with the maxim of "each according to his ability".

[36] If there are "out-of-pocket expenses", it is because we accept that they exist.

[37] A. Sen (1999). L'économie est une science morale. La Découverte/Poche, 126 pp.

[38] Marmot M, Allen J, Goldblatt P, Boyce T, McNeish D, Grady M (2010). Fair Society, Healthy Lives: The Marmot Review. London, Institute of Healthy Equity, 238 pp.

At the heart of the matter, therefore, is **the need for citizens to be recognised, individually and collectively, not only as recipients of public healthcare, but also as players in it**.

Public health is also a "public good" in the same way as some of society's primary assets and democratic decision-making in general.
Integrating public health into common goods (see Box 2), into the general interest and into democratic processes will be a step forward for both democracy and health itself, as it is a prerequisite for trust, and therefore also for the support and behaviour without which public health is not possible.

**Box 2: The notion of "common good"**
The notion of a "common good" refers to goods that cannot be used exclusively (i.e. "owned" by some as opposed to others), because of their importance to the community as a whole; this notion, which is at the heart of environmental issues, also applies to public health, and concerns both "natural" objects (air, water and their minimum quality) and "technical" objects (the minimum care, medicines and treatments, such as vaccines, necessary for the minimum survival of human communities).

The following two aspects should therefore be highlighted: (1) thinking of the ethical framework of public health as the foundation of public policies, a public health that develops everyone's "power to act" in the construction of a common good; (2) enshrining the principle of co-construction of this common good by relying on the implementation of participatory tools, in other words through **genuine citizen participation in health**. This is characterised by participation at all levels, not only as a citizen, but also as a health player, a professional, a patient, a local player in "community" health in the professional, local, educational and, more generally, social environment.
At the end of the General Assembly on Ethics and Public Health, proposals must be put forward on how best to implement this citizen participation, which is also a prerequisite for a healthy democracy.

**Ethical reflection in general questions the principles that define the very notion of progress,** understood in a broad and deep way. Progress must integrate the notion of justice and temporality, avoiding a short-term vision in favour of a vision driven by sustainability for future generations and the planet. Ethical questioning is made more difficult by the complexity of the issues it addresses, which take on multiple aspects: the complexity of the way living organisms function; the complexity linked to the growing divergence of convictions in society, where no way of life is any longer based on a set of values accepted by all; the complexity due to globalisation and the heterogeneity of practices, cultures and even value systems.
This complexity and diversity call for reflection on how to **build a common foundation of values based on trust within society**, because not everything can be understood: if diversity is a source of tension, it can also be a source of fertility for thought, for the development and statement of values that we share in order to **build the "public health" that we want to give ourselves, i.e. a representation of the "common"** that will first and foremost involve caring for the most vulnerable .

# III. INSTITUTIONS AND CITIZEN PARTICIPATION IN PUBLIC HEALTH: CURRENT SITUATION AND OUTLOOK

The practical implementation of the ethical framework for public health must henceforth be conceived with recourse to citizen participation, exercised on an individual[39] or collective[40] basis, which is democratic in two respects: on the one hand, because it is provided for by public institutions and, on the other, because it makes it possible to respect the principles of a democracy, in particular listening to the expectations and needs of healthcare users in the decisions that concern them, and more generally in the operation of the healthcare system.
The expression "citizen participation in public health" sums up these two aspects without confusing them (see Box 3).

**Box 3: Citizen participation, health democracy, democracy in healthcare**
The term "democracy" has a very precise definition: government by the people. Democracy is political, but taking people's opinions into account is essential to good governance at all levels, particularly within the healthcare system. The terms "*démocratie sanitaire*" ("health democracy"), which are enshrined in the Public Health Code, or even more broadly "*démocratie en santé*" ("democracy in health"), primarily reflect the participation of users in health decisions that affect them individually, or more collectively as part of the operation of the establishments and services that cater for them, but also their participation in local and regional bodies, and their contribution to participatory research protocols. It is therefore a question of multidimensional citizen participation in the construction of decisions and democratic life.

It is important to take stock of the existing institutions and systems (A), before outlining the prospects for citizen participation, the most vulnerable groups in particular and the new contexts (B).

As with all the subjects addressed in this Opinion, these questions are also likely to be the subject of future work by the CCNE and are therefore indicative, requiring more detailed consideration. But these indications will make it possible to outline the **framework** proposed in this Opinion, which will **focus on trust, democratic participation and time scales**, as well as the **formulation of a summary proposal**.

## A. STATE OF PLAY: LAWS, INSTITUTIONS

[39] It is an expression of choice, consent or refusal of consent.

[40] The aim is to ensure the participation of user representatives in bodies such as users' committees, social life councils, regional health and autonomy conferences, territorial health councils and national health conferences.

A quick overview of the concept of public health in French law shows that the notions of health policy and public health have almost become confused. The evolution of the texts (Annex 3) is highly instructive in terms of the emergence of the concept of public health, its evolution and the fundamental role it now plays in defining health policy. It also highlights the notion of public order and health security, which is at the heart of public health.

These demands have led to a focus on the "common good" rather than the freedom of the individual or of trade and industry (for example, the fight against smoking or the excessive use of alcoholic or sugary drinks).

Article L1110-1 of the Public Health Code, resulting from the law of 4 March 2002,[41] is innovative in its wording: "The fundamental right to health protection must be implemented by all available means for the benefit of everyone. Health professionals, health establishments and networks, health insurance bodies or any other bodies involved in prevention and care, and the health authorities will contribute, together with users, to developing prevention, guaranteeing equal access for all persons to the care required by their state of health and ensuring continuity of care and the best possible health security."

**In addition to the traditional notion of prevention, there is also that of access to care and health security.** These are three of the main areas of public health. The mention of "users" also reveals the emergence of the patient in the definition of public health policy.

The Law of 9 August 2004 on public health policy,[42] passed more than a century after the first public health law, defines public health policy for the first time in article L1411-1 of the Public Health Code.[43] The responsibility of the State is clearly affirmed. Reducing health inequalities is promoted as a public health objective, as is improving the state of health of the population and the quality of life of sick and disabled people.

With the Law of 26 January 2016 on the modernisation of the healthcare system,[44] the five-year programmes disappear; the term "public health" is no longer mentioned in the wording of article L1411-1 of the Public Health Code (Annex 3). Health policy is part of the national health strategy, a concept launched in 2013. The objectives are very ambitious.

As indicated in the report by the National Assembly's Law Commission, the State's area of intervention "is no longer restricted to 'public health', but covers the entire field of health: prevention, health security and hospital establishments, as before, but now also, unambiguously, the fields of 'health risk' management, which the Social Security Code entrusted to the managing bodies of the health insurance scheme and which cover the management of outpatient care and the coverage of insured persons' expenditure".[45]

---

[41] Law No 2002-303 of 4 March 2002 on patients' rights and the quality of the healthcare system.

[42] Law No 2004-806 of 9 August 2004 on public health policy.

[43] See Annex 3.

[44] Law No 2016-41 of 26 January 2016 on the modernisation of our healthcare system.

[45] It is this last point that is the subject of 6°, of which there is no trace in the previous version of article L1411-1. But the other elements of the definition relate to public health objectives. 1° affirms that a broad vision of health policy and the factors likely to influence it is taken into account by including "the concept of the exposome, understood as the integration over a lifetime of all the exposures that can influence human health"; see also note 16.

This law is thus set out in the National Public Health Plan[46] presented in March 2018, which is extremely ambitious in that it includes a large number of highly varied actions designed to cover all ages of life (25 measures tailored to life stages).

**As far as institutions are concerned,** it cannot be said that there is a lack of bodies for consultation or expertise in public health. There are certainly many of them, but they are not necessarily well coordinated with each other or even approached and listened to by the public authorities. While it is not a question of creating new structures, would it not be appropriate to reflect on how best to use them, to ensure greater cooperation between existing scientific institutions and to avoid any overlapping of responsibilities?

These bodies include consultation bodies:
- The Economic, Social and Environmental Council (*Conseil économique, social et environnemental*) – which has three main missions (to advise the government, promote dialogue "between the nation's driving forces" and contribute to informing Parliament) – was reformed in 2021, in particular to include the voice of citizens in the work of organised civil society;
- The National Health Conference (*Conférence nationale de santé*) (and the regional conferences on health and autonomy (*conférences régionales de santé et de l'autonomie*)), the main body for health democracy, is the equivalent of a Health Parliament with 96 full members (and 96 deputy members) divided into five colleges, bringing together representatives of civil society and other health stakeholders.

There are also advisory bodies for scientific expertise in public health:
- Santé Publique France is the national scientific reference agency for public health. It is responsible for constantly monitoring the state of health of the population and its evolution, in order to inform the development and evaluation of policies to improve and protect health. It is involved in all areas of public health: prevention and health promotion, monitoring and observation of the population's state of health, surveillance, alerts and investigations, helplines for populations in difficulty, preparation for and response to health crises, in particular by mobilising a health reserve to bolster the healthcare system and, on behalf of the State, by acquiring, storing and distributing strategic stocks of health products.
- The Haut Conseil de la Santé Publique provides expertise in health risk management and contributes to the preparation, annual monitoring and multiannual assessment of the National Health Strategy, as well as to the design and evaluation of health prevention and safety policies and strategies.[47]
- The Haute Autorité de Santé is an independent scientific public authority with a number of missions, including medical, economic and public health assessment, improving the quality and safety of healthcare, and informing healthcare professionals and the public. It evaluates the quality of preventive actions and programmes, particularly those involving health education, diagnosis or care.

There are also a large number of specialised health agencies that issue expert opinions in their relevant fields, while leaving the final decision and strategy to the authori-

[46] https://www.temporel.fr/plan-national-de-sante-publique-la-prevention-contre-les-inegalites-de-sante
[47] The Haut Conseil de la Santé Publique has five permanent working groups: influenza, coronavirus, emerging respiratory infections; comprehensive and concerted child health policy; national health strategy and indicators; safety of human body components and products; social inequalities in health.

ties,[48] as well as *sui generis* expert bodies such as the Académie de Médecine and the Société Française de Santé Publique, which is made up of legal entities and individual members[49] and deals with all issues relating to public health. Their work is based in particular on a critical analysis of scientific facts and professional practices, and enables them to formulate proposals for decision-makers and, via the media, to enlighten public opinion on the challenges of health policies and the strengths and weaknesses of their implementation.

**In the CCNE's view, the multiplicity of bodies and the lack of coordination between them are detrimental to understanding the major role that public health should play.** They probably contribute to limiting effectiveness in the design, implementation and evaluation of healthcare policies. Unfortunately, they do not enable us to understand the basis and ethical aim of these policies.

There is a tension between defining a public health policy and establishing a public health ethic. Indeed, public policy is always geared towards building a social group, a "polis", and to this end aims to achieve a fair organisation (at least in a democratic system). Can the ethical framework of public health, which is primarily conceptual, also generate practices? Are ethics not an explanation of the presuppositions of political action, bringing out the essential elements of political action?

## B. PERSPECTIVES: CITIZEN PARTICIPATION, POPULATIONS, CONTEXTS

The foregoing has enabled us to identify the steps that have already been taken, as well as those that still need to be taken in two complementary directions:
- simplifying public health institutions around a central principle: social and civic participation;
- complementing the actions of healthcare institutions in two main areas: vulnerable populations and the global, long-term context, from education to international affairs.

First, we need to look again at the mechanisms for participation in public health and governance, to complement them and simplify them at the same time.

The first principle, as set out in the 2002 law (see above), is that of **patient participation**:
- the patient, together with those involved in his health in general, participates in drawing up a decision concerning his care and treatment (a decision reserved for the patient, if he is able and wishes to do so).

[48] In view of their number, a committee to coordinate the agency system has been set up, reporting to the Minister for Health, to coordinate the work of the Établissement français du sang, the Agence nationale chargée de la sécurité sanitaire de l'alimentation, de l'environnement et du travail, the Institut national du cancer, the Agence de la biomédecine, the Agence nationale de sécurité du médicament et des produits de santé, as well as the Haute autorité de santé, the Autorité de sûreté nucléaire and the Institut de radioprotection et de sûreté nucléaire. It ensures the quality of their interactions and the harmonisation of their practices, in the interests of public health and health security.

[49] The Société Française de Santé Publique brings together hygienists and clinicians, pharmacists and biochemists, veterinary surgeons and agricultural engineers, health engineers and legal experts, architects and town planners, local councillors and politicians, etc.

- It is also involved in shaping health policy (decision-making being the preserve of politicians), through consultation, deliberation and collective governance in public health.
So far, there have been two stages in this principle of participation, and now we need to move on to the third, the importance of which has just been underlined by the pandemic:
- the stage of individual consent, from the principles of bioethics to the law of 2002; and this is still evolving (see CCNE Opinion 136);
- the stage at which patients and healthcare professionals in general are represented in a specific crisis or pathology: here, the experience of AIDS has proved decisive historically, sociologically and politically. On the other hand, the consultation of society as a whole during the Covid-19 health crisis proved to be inadequate and flawed.
Concerned in all areas, and in a necessary relationship with science and medicine, society would probably have gained confidence in those responsible for health policy as well as in medicine, had it been involved in the reflections, doubts, then orientations and decisions during this period.
In this sense, could we not compare **the principle of public consultation, in the context of public health, with individual consent in the context of healthcare**?

But it is important to build it in a specific way, both through governance and through consultation with society at all levels, including the most local or "community" level, i.e. in all areas of social life.

Public health is an interaction between disciplines and professional and/or lay knowledge. The question here is how to build the capacity to encourage different population groups to adopt health-promoting behaviours. As emphasised by the National Health Conference (*Conférence nationale de santé*): *"Mobilised healthcare democracy guarantees the capacity for action at individual and population levels. It is the lever for 'acting together' and for greater solidarity. It is the prerequisite for effective, efficient and ethical decision-making, including (and perhaps even more so) in health crisis situations."*[50]

Thus the need for genuine citizen participation in healthcare is clear. But this dimension of participation in health is a complex field that involves other aspects of human life in its operation: education, trust, participation, inequalities, information, "capabilities" in the sense proposed by Amartya Sen.
In this Opinion, the CCNE can only emphasise the **urgent need to consider the conditions that would enable citizen participation in public health to be effective and lasting**.

The health crisis has raised the question of the value of "health" in relation to the value of a "good life". What is a "right to health"? Do we only live to be in good health?
In public health, "collective" health and the preservation of the healthcare system take precedence. At a population level, what we might call "collective" health should be the objective of a policy, but it rarely is at the level of the individual, thus summing up the fundamental tension already mentioned.

[50] Conférence nationale de santé (2020). La démocratie en santé à l'épreuve de la crise sanitaire Covid-19, opinion of 15 April 2020, 14 pp.
https://solidarites-sante.gouv.fr/IMG/pdf/avis_cns2_150420_cp_revu_er_env_2206_250620_espace.pdf

But between these two extremes, it is important to highlight the specific case of certain **social categories**.

A second series of concrete perspectives would therefore focus on specific populations characterised by their **vulnerability**.
The health crisis has brought to light situations of extreme hardship, mainly affecting the most disadvantaged individuals and families, migrants and the homeless, people living in places where people are deprived of their freedom, people with disabilities and the elderly, particularly those in a state of dependency in dedicated accommodation. Children and students have not been spared, given the successive periods of fragility and the collateral effects of the pandemic crisis.
This necessarily implies looking at the way in which these specific populations emerge precisely as a "population category": how do priorities emerge for considering them as "target" or priority populations for public health? Why and how do migrants and refugees, or "people in precarious situations", fail to feature in these priorities?

Although they are very diverse, migrants and refugees are treated in the same way, regardless of their individual characteristics and specificities. They share a common characteristic, that of wanting to choose where they will live freely and with dignity, but they are treated according to only one criterion: whether or not they are allowed to enter the territory of their choice. Their regulatory and social treatment is undifferentiated and based on very general regulatory considerations that are constantly changing and unevenly respected by the authorities. This is why immigrants are treated as a group, rather than as individuals, for social and protective reasons, as long as they do not have valid residence permits;[51] this often has very serious consequences in terms of health and access to healthcare, even though protecting individual and collective well-being is the ultimate aim of public health.

Another revealing example of the fragility of society and public health policies concerns the dependent elderly population,[52] insofar as this section of the general population (and the corresponding age bracket) was also the most exposed to the lethal and collateral effects of the Covid-19 epidemic. A better understanding of the tension between the application of public health measures of obvious collective interest, the preservation of the country's economic potential and the preservation of the respect and dignity of the most vulnerable people constitutes a necessary ethical approach enabling a better understanding of public health and an illustration of the contribution of an ethical framework to the development of public health policies, in this case the need to rethink policies to support ageing and to strengthen the palliative approach in care settings.

Finally, the public dimension of health implies a certain number of **contexts** that need to be taken into account in the long term, but also now, ranging from **the education of new generations to the international and global environmental context, and including teaching adapted to the specific and transdisciplinary dimension of the field**.

[51] This can take an average of three to four years.

[52] As part of this ethical reflection on public health, and in conjunction with the platform of proposals that formed the Covid-19 Ad Memoriam Institute (https://www.institutcovid19admemoriam.com/), the CCNE recently proposed drawing lessons from the health crisis, specifically with regard to dependent elderly people.

- *General education-prevention*. This has already been emphasised, but public health education must not be reduced to the simple notion of prevention. Public health, because it is population-based, must be disseminated on a population basis. Public health education should have a prominent place in school education programmes. But if it is to achieve its objective – to empower individuals to take responsibility for their own health and for the health of the community as a whole – it must be conceived in a multifaceted, cross-disciplinary way: prevention, of course, but also information on the rights of individuals, on the structures that exist, on the various players involved in health, on the costs and the individual and collective challenges of the health system. Is not the ultimate aim to acquire, through education and information in particular, the individual autonomy needed to grasp the challenges of public health, particularly those that involve the individual?

- *Public health education*. Public health teaching for public health students is still largely confined to medical faculties. The multidisciplinary nature of public health has been emphasised in this Opinion; it would be desirable for public health teaching to be the preserve not only of doctors, but also of anthropologists, philosophers, historians, economists, veterinary surgeons, agronomists – in other words, as many medical disciplines as life sciences, as many humanities and social sciences as earth and environmental sciences.

There is also the now global context of public health:

- *Global health is inextricably linked to the environment.* There is now a broad consensus that humanity, as a stakeholder in the planetary ecosystem, is facing an "environmental crisis", i.e. a biological, climatic and social crisis, largely caused by its own activities. Furthermore, according to the World Organisation for Animal Health, 70 to 80% of transmissible diseases have an animal origin (reservoirs of viruses or other pathogens), while epidemiological studies also emphasise that changes in the ecological environment, as a result of pollution and the destruction of natural areas, partly explain the emergence of new human diseases, in particular by having favoured the vectors of these diseases and contact with them.[53] A factor such as air pollution, favoured by large urban concentrations, caused the premature death of almost 9 million people worldwide in 2015, including 600,000 children, according to a study published in the *European Heart Journal*. Although climate change and environmental disruption are partly independent, they can combine to threaten human health.[54]

Awareness of the deterioration in human health linked to the "ecological crisis" is becoming particularly urgent. We often have to wait until we are directly confronted with the consequences of the "ecological crisis" before we accept the urgency of taking action.
This collective and individual awareness is inevitably reflected in a number of attitudes and ethical approaches: questioning the consequences of our actions, but also their causes, i.e. the ways in which we interact with other members of humankind and all living things; rethinking our relationship with the living world by rediscovering a sense

[53] Emerging infectious diseases are on the increase worldwide (new influenza viruses, chikungunya, Ebola, Zika, etc.) and account for 14 million deaths a year.

[54] It is also worth remembering that today, according to the UN, one person in nine in the world suffers from hunger and three people in 10 have no access to drinking water.

of limits and considering its fragility, its dynamics and its contribution to human societies; questioning the concept and meaning of progress (including scientific progress) by placing them in a systemic vision, including the economy and well-being.

This awareness must permeate and become a major issue likely to lead to executive and managerial decisions of many kinds, but also to appropriate communication. How can we help "ethically arm" public and economic decision-makers and private individuals? How can we promote ethical reflection at grass roots level? How can we get local authorities, and businesses in particular, to take on board these environmental and health concerns?

- *The concept of One Health*. As emphasised in CCNE Opinion 125, human health, animal health and the health of the ecosystem are one and the same, justifying a multidisciplinary approach. The concept of One Health, first used by William B. Karesh in an article on Ebola in 2003[55] and later confirmed by Joseph Bénié Bi Vroh,[56] is the expression of this: *"Human or livestock or wildlife health can't be discussed in isolation anymore. There is just one health. And the solutions require everyone working together on all the different levels."*
This concept – which is based on the relationship between the environment and health – is part of a global health security framework, strengthening the international community's ability to anticipate risks and mitigate the effects of crises arising from interference between humans, animals and ecosystems.

- *International perspective*. The above discussion of the concept of global health raises the question of how it can be put into practice.[57] Health issues are no longer considered at national or regional level, but from a global perspective through a highly interdisciplinary approach. This is immediately part of a political objective: to call for collective and coordinated responses across the planet. But do existing international institutions, such as the WHO, currently have the resources to drive global health policy? The pandemic raised awareness of our collective vulnerability and of the interdependence between countries.

There is therefore an urgent need to think about health beyond territorial, disciplinary and sectoral boundaries, in order to design effective global health governance that does not forget the ethical issues at stake: justice, equity, autonomy, equality between countries, non-maleficence, democracy, and so on.[58] Should we not be looking at the fit between the organisations currently responsible for global health and the increasingly urgent needs that need to be met?

---

[55] Weiss, Rick (7 April 2003). "Africa's Apes Are Imperiled, Researchers Warn". The Washington Post. Retrieved 2017-08-20.

[56] Bénié Bi Vroh J, Seck I. La mise en œuvre du concept One Health est-elle une réalité en Afrique ? *Santé Publique* 2016 ; 28 : 283–285. According to Joseph Benie Bi Vroh, this is "an integrated approach to health that focuses on the interactions between animals, humans and their various environments", encouraging "collaboration, synergies and cross-fertilisation between all sectors and players whose activities may have an impact on health".

[57] S. Tchiombiano (2020). Pandémie 2020. Éthique, société, politique (edited by Emmanuel Hirsch). Les éditions du Cerf, Paris, 845–852.

[58] The WHO set up an independent panel to review pandemic preparedness and response, which published its second report in January 2021. The report showed that, before the crisis, many diagnoses and recommendations for improving crisis preparedness had been made, but they were rarely taken into account, either at national or international level.

On a slightly different scale, we also need to look at the existence – or absence – of global health policies at international, regional and even national level. Thus it is striking to note the diversity of responses to the Covid-19 crisis in the member countries of the European Union: some were radically different. It is equally striking to note the absence of a coordinated response at European level to managing the crisis, or at least to establishing a joint management programme, even though, by its very nature as a pandemic, there would have been – and still is – a need for coherent collective behaviour.

Thus thinking about public health at a global level is both the starting point and the horizon for achieving public health that is ethical and, indeed, public.

# CONCLUSIONS AND RECOMMENDATIONS: TRUST AND PUBLIC PARTICIPATION IN PUBLIC HEALTH, BETWEEN URGENCY AND THE MEDIUM AND LONG TERM

In conclusion, it is necessary to return to **two general and complementary dimensions** which have underpinned this reflection on public health ethics, and which it would also be necessary to articulate, as current experience shows, according to the **three temporal dimensions of the emergency, the medium term and the long term**, leading to a summary **proposal** which would make it possible to give concrete expression to the general framework outlined in this Opinion.

The **two general and complementary dimensions** of public health ethics are:
- respect for **ethical principles** in public health policies aimed at society as a whole;
- and the resulting increase in the **confidence** of the public and healthcare professionals **in these policies** and in the healthcare system, confidence which is the key to their implementation and which is, in a way, the criterion for public health that respects ethical criteria.

Here we find the two axes of public health: policies aimed at society, or the behaviour of citizens, with a view to health. We also find the two problems they can pose: tension with individual health and inevitable population trade-offs on the one hand, resistance and ambivalence on the part of the players themselves on the other, as well as the two orders of reference for responding to them: the principle of justice, the common good and the general interest; the principles of bioethics and respect for the individual.

**Respect for public health ethics and trust in public health are therefore two facets of the same objective:** they are mutually dependent if we are to achieve the goal of public health serving the general interest.
Respect for ethics, through the actions implemented, conditions the confidence of citizens in policymakers, reinforcing this respect in return.[59]

However, we need to complete this bimodal presentation by modulating it according to a temporal dimension, which has run through the whole reflection and which is also its backdrop in the Covid-19 health crisis, while also recalling that public health choices are profoundly political, resulting in particular in the allocation of resources.

These guidelines and benchmarks will always have to be broken down into three inevitably distinct areas, each with its own requirements:

[59] This virtuous circle contrasts with the vicious circle of mutual distrust between political institutions and society, and vice versa.

- **crises and emergencies,** which need to be anticipated and prepared for, bearing in mind that the unforeseen must be capable of arising, but which also have something inevitable and unexpected about them every time; while a crisis implies a time of crisis and emergency, it also implies its aftermath, which begins, in the case of the current health crisis, when it is not yet over. The CCNE itself has sought to accompany the health crisis by showing how ethical principles can be maintained, particularly with regard to vaccination methods and support for the elderly. Other urgent issues, concerning immigrants and those without resources, will have to be dealt with in the same way;

- **the medium term,** with the establishment of balances and trade-offs in the health, economic, social and political fields in general, and the simplification of institutions for consultation, participation and decision-making; health information and health democracy are two examples of projects to be investigated in this context, as they are consubstantial with autonomy in public health;

- **the long term,** including education, teaching and the global dimension, as well as the organisation of the healthcare system on a public health basis, incorporating occupational health and the relationship between health and the environment.

All of this leads to a **summary proposal**, which will summarise this Opinion, which was itself intended to provide a general framework for considerations and subjects, some of which have already been dealt with, or are still to be planned.
This proposal is itself a response to the event that prompted this reflection (see Box 4): putting public health issues back at the heart of healthcare, and of society as a whole.

**Box 4: Implementation of the General Assembly on Public Health Ethics**
The CCNE is proposing that the General Assembly on Public Health Ethics be set up, in coordination with national or regional public health bodies and regional ethical think tanks for the ethical aspects of public health.

This **General Assembly on Public Health Ethics** should be an opportunity to deliberate collectively on actions to be taken with a view to co-constructing the common good that public health represents.

# ANNEXES

## Annex 1: Composition of the working group

Mounira Amor-Guéret

François Ansermet

Régis Aubry (rapporteur)

Alain Claeys

Sophie Crozier

Marc Delatte

Annabel Desgrées du Loû

Emmanuel Didier

Pierre-Henri Duée (rapporteur)

Florence Gruat

Claude Kirchner

Florence Jusot

Karine Lefeuvre

Caroline Martin

Dominique Quinio

Frédéric Worms (rapporteur)

*With the editorial support of Lucas Nagot (Sciences Po, Paris)*

## Annex 2: List of people interviewed

Franck Chauvin (Haut Conseil de Santé Publique)

Florence Jusot (University of Paris-Dauphine), Clémence Thébaut (University of Limoges and Paris-Dauphine) and Jérôme Wittwer (University of Bordeaux)

Laurent Chambaud (École des Hautes Études en Santé Publique)

Annabel Desgrées du Loû (IRD, Global Health 2030)

Emmanuel Rusch (National Health Conference and French Public Health Society)

Alfred Spira (Académie nationale de médecine) and Louis Barda (Médecins du Monde)

Didier Sicard (Honorary President of CCNE)

Daniel Benamouzig (CNRS Research Director, Sciences Po Health Chair and Centre de Sociologie des Organisations)

Michèle Delaunay (former Minister for the Elderly and Autonomy)

Mathias Girel (ENS – philosophy department)

Kristine Sørensen (Global Health Literacy Academy, Denmark)

## Annex 3: A history of public health through the prism of law

Public health policy was originally a response to epidemics (plague, cholera, smallpox) and the damage caused by insalubrity. The passing of the first public health laws gave rise to conflicts that revealed tensions between the rights of the individual and the collective interest. Thus the law of 13 April 1850 on substandard housing, which was designed in particular to reduce the number of deaths caused by indecent housing conditions, encouraged local authorities to intervene to force landlords to carry out work in the most serious cases. It was not well received by property owners, who felt that it infringed their right to property. It should be noted that this very social law was also the first component of a housing policy.

The law on the protection of public health of 15 February 1902 introduced the term "public health" into the legal vocabulary and followed on from various earlier laws on vaccination against smallpox, on the declaration of diseases such as the plague, leprosy and cholera, and on disinfection; it adopted a hygienist and preventive approach to public health with a threefold objective: to vaccinate, declare and disinfect. Although the law, which affirms the primacy of the rights of the community over those of the individual, was adopted without too many problems, it should also be remembered that compulsory vaccination was rejected by some as an infringement of individual freedom or as a gesture detrimental to the dignity of the human body.[60]

The law was conceived in part as an element in the fight against a new form of war, the war for health: one senator saw it as a "vital issue for our country": with peace restored, it was now "the enemy of every day, the one who surrounds us, embraces us, threatens us at every moment that we must fight". Such a conception could justify legislative provisions that restrict freedoms. Other laws will complement it in the same spirit of prevention. Public health policy is a more or less accepted universe of constraints, with its compulsory vaccinations, its rules on driving (which, incidentally, involve a body that is not a health body), its controls on the sale of alcohol and the other regulations that are developing.

From the outset, the concept of public health has had a public order component. The aim is to guarantee health safety for as many people as possible or for certain disadvantaged groups (in the case of insalubrity), even though the expression "health security" is hardly ever used.
This notion of public policy is also present in texts relating to local authorities. The current article L2212-2 of the General Local Authorities Code has its origins in article 97 of the law of 5 April 1884: "The purpose of the municipal police force is to ensure good order, safety, security and public health [with a reference also in 5° to] "preventing epidemic or contagious diseases by taking suitable precautions and putting a stop to them by distributing the necessary aid, ... providing urgent assistance and relief and, if necessary, calling in the higher administration."

[60] More than a century later, the Council of State affirmed that while the provisions making certain vaccinations compulsory or allowing the administrative authority to introduce such obligations by regulation "have the effect of causing a limited infringement of the principles of inviolability and integrity of the human body (...), they are implemented with the aim of ensuring the protection of health, which is a principle guaranteed by the Preamble to the 1946 Constitution to which the Preamble to the 1958 Constitution refers, and are proportionate to that objective": Council of State, 26 November 2001, No 222741

Then, with the progress of curative medicine, public health lost importance, even though measures continued to be taken. It returned to the spotlight with the contaminated blood scandal, the bovine spongiform encephalopathy (BSE) affair and the AIDS epidemic. This gave rise to the concept of health security, which covers a wide range of areas including medicines and food. This goes beyond the traditional aims of public health.

OPINION 137

# OPINION 137


NATIONAL CONSULTATIVE ETHICS COMMITTEE
FOR HEALTH AND LIFE SCIENCES