





Seminar of 28 November 2023

Ethical challenges for a national public health agency



Introduction

Anne-Catherine Viso, Scientific and International Department, Santé publique France

Following more than two years of reflection within Santé publique France on the challenges of ethics in public health, the agency organised an initial seminar on 28 November 2023 to lay the foundations for establishing a suitable ethical approach for the conduct of its missions to protect and improve population health.

This day marks the culmination of a decade-long process initiated in conjunction with the Ethics and Professional Conduct Committee (CED), which has included actions to raise awareness, internal consultations in 2017 and 2018, a focus session at the Rencontres de Santé publique France institutional event in 2019 and an issue of the journal *La Santé en action* dedicated to ethics, prevention and health promotion published in 2020 (Bungener et al., 2020).

This seminar represents a milestone and not an end in itself. The collective reflection and questioning generated will form the impetus for more concrete work to establish a pragmatic and deliberative ethical approach at Santé publique France.

The support and guidance provided by the CED, chaired by Grégory Aiguier, have been essential for the undertaking of this project and to the development of ethical guidance for project analysis at Santé publique France. This guidance was presented during the seminar.

This seminar, which adopted a reflective approach, was preceded by three preparatory thematic workshops that took place between November 2022 and June 2023. These were accompanied by two qualitative interview sessions with professionals and experts in public health or ethics: one was held with staff from Santé publique France and the other with external specialists. Their findings are presented here by the interviewers themselves.

The discussions that took place at the Public Health Ethics seminar drew on this wealth of material to identify relevant teachings and map out the way forward. Despite being primarily designed for internal purposes, this project represents an opportunity to bring together our partners (French Directorate General for Health, other agencies in France and abroad, etc.) to address matters of public health ethics and to implement such an approach within a national public health agency setting. This project is also an opportunity to publicise the work carried out and put it into perspective beyond Santé publique France.

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Session 1

Specificities and challenges of ethical questions in public health

Session moderated by Jean-Claude Desenclos and Grégory Aiguier

Embedding ethics into public health in the United States

Lisa M. Lee, Virginia Polytechnic Institute and State University (Virginia Tech), USA

Embedding ethics into public health practice is an ongoing process that has witnessed key advances since the early 2000s. Part of the focus has been placed on teaching ethics to professionals: What should the goals and content be and what skills should be developed? Yet implementing this requires the commitment of public health institutions and the creation of demand on the part of professionals.

In the United States, two approaches have prevailed. The first lies at the crossroads of biology and humanitarian thought, integrating the human and social sciences, the dimension of environmental health and a global reflection on ecosystems. The second focuses on aspects specific to medicine, clinical research and medical ethics. Although medical ethics has long dominated this domain, a broader concept emerged at the beginning of this millennium: public health ethics. The underlying values and principles differ from those of the ethics of medical care or research.

The challenge is to help experts in bioethics, professionals and decision-makers understand the specific features of the application of ethics to the field of public health: to explain how the principles of public health decision-making differ from those of clinical practice, leading to choices that are appropriate and based on rigorous analysis. Ethics in public health practice calls on two distinct visions: 1) the production of moral governance that responds to specific values derived from professional practices, and not solely from the rights of individuals, to legitimise reasoned choices in potentially conflicting decisions; and 2) an active decision-making framework focused on the population that is used to overcome conflicts of values. Ethics in public health is therefore a collective method of questioning that objectively considers the ethical problems of decision-making by freeing them from the personal subjectivity of the professional and/or the institution. The aim is to propose routes to action that take into account the values of both the professional and target populations.

Beginning its work in the first decade of the 21st century, the American Public Health Association (APHA) has made a major contribution to advances in public health ethics. This non-governmental professional association represents more than 50,000 public health practitioners working in all sectors of public health and has considerable scope for advocacy. In 2014, it drew up a list of ethical principles and values in public health for professionals working in this field and initiated a national deliberation, leading to the publication of a professional code of ethics in 2019. This sets out six non-hierarchical fundamental values that are considered essential and eight considerations for analysing the ethical conflicts and dilemmas raised by practice (see Annex).

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The aim is to propose routes to action that take into account the values of both the professional and target populations.

The list of collective values presupposes the existence of conflicts such as those between individual freedoms and civil rights on the one hand and the public interest on the other. This means that we must learn to manage these competing values, a core practice in public health ethics, with a view to finding solutions and taking actions that meet the expectations of the public and society.

Even though this process takes time in practice and is not always easy to apply to all decisions, especially when urgent responses are required, we must assume that it should be incorporated as a matter of routine. In this model, the skills required are the ability to identify the ethical questions raised, to resolve the associated dilemmas by considering the values of the discipline along with those of the target population, to manage consultations with the concerned populations, particularly in complex situations, and to evaluate the intervention. These steps make it possible to create a frame of reference and a body of documentation that is accessible and usable by all.

Teaching a public health ethical framework to students and practitioners is therefore essential groundwork. It is a long-term investment throughout professional life, with teaching that should be flexible and ongoing. Training is multidimensional, and where different values and developments exist, it must be open to scientific and experiential knowledge, to the new challenges and threats facing populations, and to the new public health interventions available to professionals to take action.

The US Council on Education for Public Health includes public health ethics as a competency for Master's and PhD degrees in public health. In addition, the US Public Health Accreditation Board, which accredits local and state health departments, worked with the US Centres for Disease Control and Prevention to outline requirements for all accredited departments to have a documented process for identifying and addressing ethical conflicts. These national organisations are essential partners in embedding and modelling ethics decision-making skills among professionals across the public health enterprise. Finally, these institutions actively promote good ethical practice in public health. Faced with a multitude of challenges, academic teaching alone is not enough. It is essential for all stakeholders to be involved.



How does the European Centre for Disease Prevention and Control (ECDC) integrate ethics into its practice?

John Kinsman, ECDC, Sweden

The ECDC must incorporate contextual dimensions linked to the historical, political and cultural diversity of the 27 countries of the European Union (EU) so that its work may take into account the relativity of value systems.

How a European agency can address the perspective of ethics

During the COVID-19 pandemic, the issue of school closures required us to consider how proportional and appropriate this measure was in the context of each country. Despite the wide range of school closure practices implemented across the EU, with the ECDC's opinion being that school closures should only be considered as a last resort, the decision was ultimately left to each country. Such a decision must be based on scientific knowledge applied in specific contexts, particularly cultural contexts.

The balance between protecting individual freedoms and upholding the common good is not a binary choice but can rather be seen on a spectrum. Each country has its own position along that spectrum. Factors such as society's tolerance of mortality rates and consequently the "cost" to society of preserving an individual's life come into play. When restrictions were placed on the freedom of young people to protect the health of older people, different views emerged in different countries, including the issue of the harmful effects of these restrictions on younger people. The principle of inter-generational reciprocity has been raised, meaning the extent to which the constraints borne by younger generations to protect older people can be offset, for example, with regard to the future climate challenges faced by the younger generations.

An ethical framework for peacetime and crisis situations

The COVID-19 pandemic demonstrated the difficulty of conducting a full ethical analysis during a crisis. No formal ethical framework is currently applied to the ECDC's output, but instead a set of implicit values were embedded in late 2020 during the process of prioritising groups for COVID-19 vaccination. However, questions have been raised about whether the principles of solidarity and reciprocity were fully considered in this process.

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The 'peacetime' situation for ethics is illustrated by the ECDC guidance from 2023 on the prevention of infections among people who inject drugs. Ethical considerations are made explicit in the guidance, but it remains quite generic so that countries can take into account epidemiological differences, healthcare system variations as well as political, social, cultural and ethical differences. An important ethical consideration for this document was the equivalence of care between the prison environment and the outside world based on the so-called Mandela principles (UNODC, 2015).

External interpretation of ECDC advice

Guidance from the ECDC must be adaptable to the contexts and situations of different countries. In the case of its guidance on the COVID-19 Omicron variant (ECDC, 2023), for example, the timing of its spread varied from country to country, which influenced how this guidance was received and acted on.

Differences in national value systems and cultural contexts also influence the extent to which different EU/EEA countries adopt the guidance issued by the ECDC. This can be illustrated by different ways in which countries adopt guidelines on the prevention of infectious diseases within the prison system: the Mandela principles can be interpreted differently according to the ethical and cultural context of each country.

A formal internal clearance process exists for each published scientific output from the ECDC. External consultation ensures adherence to general ethical principles such as beneficence, solidarity, autonomy and equality, along with scientific soundness and alignment with the ECDC's mandate.

Outlook and conclusion

The ECDC's new mandate puts a greater focus on enhanced prevention. Building a community of practice in preventing infectious diseases, grounded in particular in the behavioural and social sciences, will involve ethical reflection at the EU level to incorporate the diversity of values of all partners – both governmental and nongovernmental.

In the absence of a single EU framework for the ethical approval of transnational studies, ethical clearance must be obtained in each participating country for such work. The ECDC is working towards improving this practice with the aim to facilitate its optimisation.

It has been deemed crucial for lessons to be learned from COVID-19 at the EU level, particularly in terms of collective measures (school closures, lockdowns, etc.) in order to be better prepared in the future. This analysis includes an ethical component.

Ethical values depend on the context, which influences practices in different countries. While sharing fundamental values and ethical principles, advice and recommendations must be able to be adapted to the context of each Member State.



Role and functions of the French National Advisory Committee on Ethics for Health and Life Sciences (CCNE)

Laurent Chambaud, CCNE

The French National Advisory Committee on Ethics (CCNE) was founded in 1983. This long existence fosters a certain depth of thinking in terms of bioethical issues. From the outset, the CCNE focused its actions on the medical and clinical aspects that dominated bioethics at the time, due to the historical context marked by the beginnings of in vitro fertilisation (IVF) in France.

In his speech inaugurating the CCNE, French President François Mitterrand expressed the hope that it would fulfil three expectations: 'That of the people, who are looking for guidance in the sometimes-dizzying advances in science of which we speak; that of the researchers and prac-

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titioners, who often feel isolated in the face of the massive consequences of their thinking and research; and that of the public authorities, which need opinions, advice and recommendations'. At the time, President Mitterrand reiterated that bioethics and medical ethics were not dissociated from the medical, cultural and social environment. As such, they had to consider the unique dialogue between healthcare professionals and patients, in addition to the context of that dialogue, while taking into account the expectations of practitioners and the population. This dimension is perfectly reflected in the current ethical challenges in France, such as the ongoing debate on the societal issues related to the end of life.

The CCNE has 45 members – health professionals, researchers, philosophers, lawyers, and so on, including six representatives of non-profit organisations (introduced by the French Bioethics Act of 2021) – and a chair appointed for a period of three years, renewable once. The CCNE operates on the basis of government referrals relating to a specific subject or on its own initiative. The time taken to produce opinions in response to a referral can be lengthy because of the strong desire to engage in dialogue with society and share all the views expressed. Decentralisation has been practised since 2004 following the creation of Regional Forums for Ethical Reflection (Espaces de réflexion éthique régionaux, ERERs), which are attached to university hospitals and have been organised into a national federation since 2021 the National Conference of ERERs (CNERER, 2023).

The National Pilot Committee for Digital Ethics (Comité national pilote d'éthique du numérique, CNPEN), established in 2019 under the auspices of the CCNE to analyse issues relating to digital technology, has now become an independant body in its own right, while continuing to share administrative resources with the CCNE.

The opinions issued by the CCNE since 1983 are grouped into nine categories: institutions, clinical trials, legal issues, health economics, end of life, autonomy and responsibility, information and consent, filiation and cellular or molecular biology. Although none of these categories has concerned public health directly, the CCNE has recently paid attention to this area, with the publication of four related opinions since 2021. Opinion 137 'Ethics and public health' (CCNE, 2021) questions the difference between clinical ethics and public health ethics in terms of values. Here we find the concepts of social justice, solidarity and common good, as highlighted in relevant publications on the subject in the USA and Europe. Public health is also addressed in Opinion 140 'Rethinking the healthcare system on an ethical basis' (CCNE, 2022), which focuses on hospitals but is expected to be extended to the entire healthcare system. Two other opinions concern public health: Opinion 144 (CCNE, 2023) on the compulsory nature of vaccination for healthcare professionals and Opinion 143 (CCNE & CNPEN, 2023) on the ethical challenges of health data platforms.

The CCNE has four main areas of work: scientific progress, which extends the original intention behind the creation of the CCNE and is still relevant today; societal issues, including public health; the environment, including health questions that overlap with public health; and digital technology in conjunction with the CNPEN. The CCNE draws on

the expertise of thematic groups and permanent working groups. There are three possible areas of interaction between the CCNE and health agencies:

- Presenting the dynamic set in motion by Santé publique France during a CCNE plenary or technical session.
- 2. Inviting agency representatives to participate in the permanent working group on public health.
- Establishing annual meetings between the CCNE and the national health agencies on subjects on which the CCNE would like to deepen its reflections.

Finally, concerns remain about the low level of training in public health ethics subjects in France. More training is needed in ethical analysis in practice, particularly for professionals. It is therefore imperative to alert higher education institutions about their responsibilities in this area.



Session 2

Teachings from the workshops and consultations held ahead of the public health ethics seminar

Session moderated by Anne-Catherine Viso and Nicolas Lechopier

Summary of the teachings and questions arising from the three preparatory workshops

Jean-Claude Desenclos, Santé publique France

The purpose of this seminar is to integrate public health ethics into the operational management of the missions, programmes and projects of Santé publique France. These preparatory workshops aimed to provide a forum for expression, sharing and reflection on the ethical questions encountered in practice but rarely addressed, and to share our thoughts with our national and international partners. Another objective was to create a body of work specific to the agency, allowing it to contribute to the work on public health ethics carried out by the French National Advisory Committee on Ethics for Health and Life Sciences (CCNE) or the World Health Organization, for example. Far from being an end in itself, this seminar represents a 'milestone' in the development of the ethical approach that Santé publique France wishes to build.

In consultation with the Ethics and Professional Conduct Committee (CED) and the Guidance and Dialogue Committee (COD) at Santé publique France, this 'summary' seminar was structured into three preparatory thematic workshops. Two consultations were conducted in parallel: interviews with professionals working in bodies other than Santé publique France to situate the agency's approach within the broader context of public health practices, and a qualitative study of staff using semi-structured interviews (Master's thesis in Social Sciences from the University of Saint-Étienne).

The first workshop (held in November 2022, involving some 40 participants) examined ethical values in public health, the setting up of an ethical approach in a public health agency and the specificity of ethics in a decision support framework. The next two workshops (held in March and June 2023, each with over 70 participants) dealt with issues arising from staff practices. They provided an opportunity to discuss and share ideas on six themes:

investigations in the field, uncertainties, participation, health promotion, social justice as well as data and data communication.

The case study leaders were supported in their presentation, the preparation of which required them to step outside their usual practice. For many, it provided an opportunity to talk about their professional experience and to 'bring to the table' subjects that, until then, had received little or no attention.

Each workshop combined practical experience (case studies) with broader and more distanced reflection. Each theme covered took into account the context, particularly regional. The case study leaders were supported in their presentation, the preparation of which required them to step outside of their usual practice. For many, it represented an opportunity to talk about their professional experience and to 'bring to the table' subjects that, until then, had received little or no attention.

These workshops were the source of multiple observations:

- Participants' high level of interest, curiosity and engagement;
- Their desire to participate and share in order to break down barriers and move towards greater collegiality;
- The opportunity to address ethical questions that can be perceived differently or that receive little to no attention;
- The importance given to reflection;
- The high availability of Santé publique France staff for the internal qualitative survey interviews;
- The commitment and support from Santé publique France, which are necessary conditions to step back and see the bigger picture of complex ethical dilemmas;
- · Workshop feedback and resilience.

The workshops revealed the diversity of questions and contexts, linked to the breadth of the missions, fields of action, regional areas and temporal dimensions (emergencies versus planned projects). Despite this diversity, a number of overarching findings emerged: the necessity to provide decision-makers with sound information on management options; to give priority to the collective and population dimensions rather than the individual dimensions; to account for uncertainties by considering proportionality and precaution; and to promote citizen participation and shared analysis.

The internal consultation with Santé publique France staff represents only the tip of the iceberg and raises the question as to how we may encourage the participation of people who dared not speak or take part in the discussion. The workshops revealed more or less conscious needs and questions as well as expectations: a shared reference framework or guide; internal discussion forums; the role of the CED; published support and resources for deployment; training; constraints and levers for staff in their practice, etc.

The workshops also highlighted the need to ensure that professionals are not left to deal with these questions alone, thus marking a shift towards shared analysis. In particular, how can we reconcile urgency with ethical questioning, which requires time? This 'dilemma', which is very much present within the agency, means that the principle of ethical questioning should be included in response preparedness so that it can be mobilised in times of crisis.

Based on the work of the seminar, the aim is to 'find our way' to develop a common practice.



Consultations with professionals and experts from outside Santé publique France on their public health ethics practices

Marc Karim Bendiane, MKBD conseils

The external consultation was conducted through interviews with professionals and experts in public health and ethics from outside Santé publique France. This consultation was designed iteratively to accompany the three preparatory workshops organised ahead of the seminar. Forty of the fifty-two participants whom we contacted took part in the interviews. More than half of the interviews were conducted by videoconference, lasting between 30 minutes and 2 hours. More than two-thirds of participants were based in France (including in the overseas territories).

Regarding the definition of public health ethics and its specificities¹, many interviewees recounted that people generally have a poor understanding of its values and principles when compared with biomedical ethics. This gap could be bridged through training and education. The lack of operational resources (guide, reference framework, charter, etc.) and a forum for sharing and reflection only reinforce the feeling of solitude when faced with ethical questions in routine practice.

Concerning the establishment of ethics within a public health agency, many participants agreed with the need for a pragmatic approach based on the concrete needs and questions of stakeholders. Two possible avenues were suggested: the first would involve setting up a dedicated internal unit with an ethicist, while the second rather draws on the dynamics of cross-functional consultation to produce accessible collective resources.

With regard to the decision-making perspective of an agency's work, two prerequisites were put forward: firstly, external recognition by decision-makers, the system and society of the agency's

ability to influence decisions in the interest of public health; secondly, the institutional top-down leadership of the agency's own senior management. There is, however, a divergence between those who advocate for the use of a pragmatic strategy and those who uphold a regulatory position similar to biomedical ethics.

Two opposing views emerged with regard to participation. The first, more minimal, sees it as a forum for plain consultation. The second, however, is not circumscribed to promoting the acceptability of decisions but instead aims to generate, through discussion and sharing, the hybridisation of expert and lay, scientific and experiential knowledge.

Note

1. Biomedical ethics compared to public health ethics (and the specificities of the latter) are discussed in Lisa Lee's text (p. 5).

When it comes to the ethical conduct during investigations into threats, particularly environmental threats, the main difficulty lies in the breadth of potential subjects and the ethical dilemmas involved, particularly given the uncertainties surrounding field analysis.

The alternative is a global approach, although this would not necessarily suit the needs of public health professionals involved in the response to an environmental threat to health, which may entail conflicting social and economic perspectives.

In a context of scientific uncertainties, transparency means that stakeholders and decision-makers must share these uncertainties with the concerned parties. The consulted experts stressed the relative nature of the choices to be made. Dealing with uncertainties brings us back to issues of communication (i.e., how to make them understandable) and mediation with field workers to explain the limits and relativity of the knowledge in order to legitimise the choice of intervention or abstention.

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Many of the participants felt that social justice is too narrowly focused on healthcare access and fails to take into account structural inequalities, such as housing, access to resources or the fight against economic and social insecurity. One point of convergence among the participants is their shared concern about the construction of national health policies, which, for the most part, insufficiently consider different regions.

The participants noted the prescriptive nature of prevention based on individual behavioural changes, which raised a number of questions: How can we intervene with groups whose lifestyles are harmful to their health? How can we approach hidden or invisible populations without undermining their autonomy? How can initiatives be better coordinated at the local level? Several levers for action were mentioned: giving priority to local support and advice using the resources specific to local groups and regions; adapting national campaigns using local approaches and with the participation of the target populations, etc.

In terms of communication, transparency is presented as an essential and inescapable principle. Nevertheless, certain obstacles limit the scope of transparency. For example, most people understand the relative nature of knowledge, the impact of controversy and the difficulty of responding to misinformation, particularly via social media.

We need better knowledge and understanding of public health ethics, the issues involved and its practical implementation. Few participants are currently engaged in a collective dynamic to reflect on this issue. For the majority, this consultation represented an opportunity to question the place of public health ethics, with the Santé publique France approach deemed to be very useful and responding to real expectations.



Internal consultation: What are the needs and expectations of Santé publique France staff?

Clarisse Vignollet, Santé publique France

The aim of this consultation was to review how the staff at Santé publique France perceive public health ethics in order to identify levers for its implementation. Sixteen semi-structured interviews were conducted with staff from all departments of the agency, both at the head office and in regional branches, to reflect the diversity of professions, themes, contexts and ethical questions raised. Two members of the Ethics and Professional Conduct Committee (CED) also took part. Once transcribed, the interviews underwent semantic content analysis.

The first observation concerns the 'vagueness and lack of clarity' as to what ethics is for participants. Their approach is experiential, based on the actual problems encountered in the field as opposed to

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a definition of public health ethics or expertise. Most of them report a lack of consideration for this dimension: 'At work, we don't talk about it much... it's a work in progress'. For some, however, it is about analysing 'the individual interest versus the collective interest' or moving towards 'the right or the good thing to do'.

The staff see this topic in an other-worldly way, far removed from the professional practices based essentially on so-called scientific principles: 'We tend to forget, we tend to resist ethics, ethics is not our way of doing things... before making a decision, it must be scientifically and legally correct – only then can we adjust it...'. The staff give ethics a secondary role, reporting a lack of 'structured' knowledge and reflection, culminating in an absence of interlocutors: '... I'm left with questions that I consider elsewhere, not in the context of my work...'.

We observed a persistent confusion between ethics, professional conduct and legal issues, with regulations taking precedence in the framework of activities, with ethics being limited to questions where the law cannot provide concrete solutions. Thus, the strict legal framework of occupational health is less subject to ethical questioning than environmental health. Ethics would instead be used to replace legal vacuums. Added to this is a real lack of knowledge about the CED: 'I don't have many opportunities to take an interest in it ... I've never encountered it ... I don't know how to contact it ... it doesn't accompany Santé publique France ...'.

The second observation concerns the concordance between the needs of the staff and the desire to establish public health ethics. Although public health ethics is perceived as vague, staff feel a 'real need' to take action: 'We need a paradigm shift... It's fundamental, this foundation that's needed

before you start working... it's this kind of change that's difficult to implement. It's no longer optional, it's compulsory'. The challenge is to address 'the institutional crisis', helping citizens to renew their confidence in science and regaining legitimacy in the eyes of stakeholders. Ethics would also make it possible to restore meaning to the profession and improve expertise 'when faced with difficult situations or undesirable effects despite the good intentions of those involved in public health'.

Among the main ethical dilemmas cited are the issues of citizen participation, the risks of discrimination or stigmatisation resulting from the communication of data, the sometimes-misunderstood choices and priorities of the agency, the 'social marketing' occasionally perceived as a form of manipulation that undermines individual freedom, and the dependence on public policy, which may take precedence over the agency's expertise, as was the case during the COVID-19 pandemic when some staff felt poorly treated.

Finally, there is the issue of how to implement ethical reflection within the agency. After the necessary acculturation phase initiated by the seminar workshops, we need to move towards a 'collective infusion' requiring the dissemination of a particular culture with support materials to provide the 'keys' for shared analysis and action. The formalisation of ethics in practice is expected, although it should be adapted to concrete situations. There is an unanimous agreement about the need for forums for shared reflection following the example of scientific forums: 'We need several brains around the table to disseminate a common culture... We need time for discussion where experiences are freely shared'. Many also stressed the need for training.

For staff, these initiatives contribute to internal and institutional awareness of the need for ethical reflection in public health practice: 'The workshops were a time for discussion, showing that this is becoming a concern for Santé publique France; it's a signal to the outside world'.



Round table: The Public Health Ethics seminar viewed by two Santé publique France agents who participated in the workshops

Frédéric Witz,

Head of the Strasbourg Remote Assistance Centre, Public Assistance and Dissemination Department (DADP), Santé publique France

The telephone counsellors at the DADP Remote Assistance Centres provide support to many people in difficulty who use these services, but they also have to deal with the anonymity of these interactions. The situations encountered by the counsellors can be very difficult to listen to, which should be kept in mind.

Our team learned three main lessons from this seminar, two of which are directly linked to the drafting of an ethical charter for telephone counsellors with the support of the Grand Est Regional Forum for Ethical Reflection (ERER). This charter responds to the needs for guidance and adjustments in our practice and reflects the necessity to work in collaboration with the Grand Est ERER. The geographical proximity between the ERER

and the Head of the Remote Assistance Centre was an advantage. The third lesson relates to the multifaceted nature of ethical questions that concern not only the public who use our services but also the counsellors who provide the service. Indeed, 'caring for others' does not exclude the need for 'self-care'.

Taking part in this seminar reinforced our conviction that ethics is omnipresent but that we are mostly alone left alone to deal with ethical issues. All the situations encountered show that despite the declared lack of staff training in this area, ethical questions are identified on an ongoing basis in the course of their work. The more difficult the situation seems to be, the more isolated and alone the staff member feels. This feeling is subjective because they are objectively part of a team. Triangulation, in the sense of being able to call on others, is a particularly important element that should be promoted. This seminar provided us with theoretical elements such as the concept of 'syndemics' (Singer et al, 2017), although it also opened up the participants' thinking towards other complexities marked by new ways of thinking and working

Taking part in this seminar reinforced our conviction that ethics omnipresent but that we are mostly left alone to deal with ethical issues. All the situations encountered show that despite the declared lack of staff training in this area, ethical questions are identified on an ongoing basis in the course of their work.

together. Establishing an ethical framework within the institution to enable the formalisation of ethical questioning will provide staff with the necessary methods and reflective skills, thus helping them to look at the bigger picture. In conclusion, this should enable the emergence of a common culture that can be shared by different specialists working in different fields who do not necessarily use the same language.

Viêt Nguyen Thanh,

Head of the Addictions Division, Prevention and Health Promotion Department (DPPS), Santé publique France

The DPPS, which includes the division of which I am the head, runs a number of initiatives with social marketing, such as 'No Smoking Month'. These programmes and actions raise specific ethical questions, which vary according to the nature of the campaigns. Although these questions are systematically considered and discussed by the teams who design and evaluate the campaigns, there had been no process for sharing reflections and reporting on the method used to construct the actions. As such, the DPPS had no formal system in place, as was the case in the agency's other departments and divisions. We found it necessary to remedy this lack of capitalisation in order to gain a better understanding of the diverse ethical questions affecting the agency, particularly in the field of prevention and health promotion. In addition to the formal discussion forums (Ethics and Professional Conduct Committee [CED] and the Internal Professional Conduct Committee), the need for appropriate tools became a clear priority, particularly for analysing social marketing campaigns. This specific

In addition to questions specific to the DPPS, the workshops highlighted the profusion of ethical questions within the agency, with numerous examples and case studies showing the need for staff training, as well for structured and shared discussions on the subject.

activity gave rise to an opinion paper from the CED (2020), which provoked a great deal of discussion within the agency. In addition to questions specific to the DPPS, the workshops highlighted the profusion of ethical questions within the agency, with numerous examples and case studies showing the need for staff training, as well as for structured and shared discussions on the subject. Staff should not have to tackle these ethical issues alone, as they can bring several value systems into conflict. On the one hand, there needs to be reciprocity, and on the other, training and tools for public health ethics should be developed to provide guidance that can be shared by all staff. Finally, these exchanges and sharing should not be confined to the agency but should turn outward, both to our partners and to the populations concerned.

Session 3

How can ethics be implemented in a public health organisation?

Session moderated by Michel Désy and Enguerrand du Roscoat

Institutionalising pragmatic ethics within Santé publique France

Grégory Aiguier, School of Social Sciences (ESSLIL); Centre for Medical Ethics (CEM/EA 7446 'Ethics'), Université catholique de Lille; Chairman of the Ethics and Professional Conduct Committee (CED) of Santé publique France

Introducing ethics into a public health agency means considering the ethical questions raised by the practice of public health, such as the tensions between individual aspirations and collective health, health democracy, citizen participation, moral pluralism and the questioning of expertise or authority. While the COVID-19 crisis is often used as an example, others are just as emblematic, such as France's 'contaminated blood' scandal. For a public health agency, in order to 'do the right thing' from an ethical perspective, its value framework needs to be continually assessed and updated to keep pace with societal and cultural changes.

From this perspective, substantive approaches to ethics founded on pre-existing philosophical and moral tenets show their limitations. The work carried out during the three discussion workshops held prior to the summary seminar clearly highlighted this dimension. While substantive approaches to ethics make it possible to produce an ethical discourse about practices, they do not not deal practically with the complexity of the situations to which a public health agency must respond.

Ethics should thus adopt a pragmatic and contextual approach (Maesschalck, 2011). This involves looking at the conditions for action in public health: (re)situating norms in different life contexts, focusing on people, their lives and their experiences, and considering ethics as a collective and continuous learning process. Therefore, ethics is not just about the application of impersonal and decontextualised standards or principles. It is the ability to co-determine the nature of problems, co-construct systems or actions to deal with the identified problems and participate in the evaluation of practices.

This approach presupposes an individual and collective commitment to the reflective and parti-

cipative governance of public health actions. The institutionalisation of ethics therefore involves defining the organisation's 'ethics project' and supporting the development of the skills needed to integrate ethics into the practices of its staff through the establishment of mechanisms, activities and resources.

It is means situating ethics within the organisation so that it is not left on the fringes of the functional organisation; it also means continuously developing the necessary skills and making practical methods and tools available, such as the document 'Repères pour l'analyse éthique à Santé publique France' (Guidance for ethical analysis at Santé publique France) finalised in November 2023.

At the public health agency level, it is therefore necessary to define what we expect of ethics: to produce recommendations for good practice, to issue advisory opinions, or to support the ethical reflections of staff? In all cases, the practice of ethics necessarily involves the interaction between two major dynamics specific to public health: the individual and collective regulation of action. Although it is necessary to respond to external standards, making staff more independant is a central objective of public health ethics.

Institutionalisation implies the need for organisation and management to sustain the ethical approach and make it a lasting part of an agency's agenda. It means situating ethics within the organisation so that it is not left on the fringes of the functional organisation; it is also about continuously developing the necessary skills and making practical methods and tools available, such as the document 'Repères pour l'analyse éthique à Santé publique France' (Guidance for Ethical Analysis at Santé publique France) finalised in November 2023.



In line with the recommendations of the latest reference framework from the French National Authority for Health (<u>HAS, 2022</u>), as well as Opinions 137 and 140 of the French National Advisory Committee on Ethics for Health and Life Sciences (CCNE) (<u>CCNE, 2021 & 2022</u>), citizens must also be involved in the ethical process.

Therefore, in this model, what is the role of a committee such as the Santé publique France Ethics and Professional Conduct Committee? Although the latter has the capacity to deal with certain situations, it must not 'appropriate' ethics but remain one of many resources with a specific mandate. As part of a more integrative approach to ethics (Hartman et al., 2020), it is possible to add other resources such as forums for reflection, which facilitate stakeholder sharing, reflectivity and agency¹.

In conclusion and as an introduction to the discussion, the institutionalisation of pragmatic and contextual ethics contributes to the 'capacitation'2 of stakeholders and the agencies themselves. It means increasing awareness about the questions that emerge from practice. This is followed by a form of 'empowerment' promoted by an ethical approach and, finally, an emancipation with the sharing of doubt and uncertainty, which to some extent goes against public health training with its predominant culture of expertise. This is in line with Paul Ricœur's thoughts on ethics as 'aiming at (tending towards) the good life (giving meaning to one's actions), with and for others (participation), in just institutions (which create the conditions to make this life better)' (Ricœur, 1990).

Notes

- 1. In psychology, agency refers to a person's ability to feel control over their actions in the world, as opposed to being subject to exterior forces. Agency may or may not be conscious, and it may or may not be intentional.
- 2. In sociology, capacitation is the process by which individuals take charge of their own economic, professional, familial and social destiny.

Round table: Proposals to facilitate ethical deliberation and reflection in professional practice

The aim of this round table was to share the experiences and thoughts of public health professionals working for Santé publique France, other agencies in France or abroad, an ethicist and representatives of associations or civil society, about how to include ethical questioning in public health. This round table was preceded by an introduction by Grégory Aiguier on the characteristics and conditions for establishing an ethical approach within an organisation. The key discussion points between the various speakers are set out below in four parts according to their institutional affiliation: Santé publique France, other agencies in France and abroad, regional forums for ethical reflection and representatives of civil society and associations.

Catherine Aumond, Chief Administrative Officer of AIDES, France; member of the Board of Directors of Santé publique France; Micah Bass, Centers for Disease Control and Prevention (CDC), USA; François Beck, Prevention and Health Promotion Department, Santé publique France; Maryse Fiorenza-Gasq, French National Conference of Regional Forums for Ethical Reflection (CNERER), France; Lisa King, Epidemiologist, Pays de la Loire Regional Office, Regions Department, Santé publique France; Mireille Lacroix, Ethics Committee, Public Health Agency of Canada, Canada; Gérard Lasfargues, Scientific Integrity Officer, National Agency for Food, Environmental and Occupational Health and Safety (ANSES), France; Yann le Strat, Data Support, Analysis and Processing Department, Santé publique France; Michèle Morin-Surroca, Prospective, French National Authority for Health (HAS), France; Stéphanie Vandentorren, Equity and Social Inequality in Health, Scientific and International Department, Santé publique France; Eric Vindimian, Guidance and Dialogue Committee (COD), Santé publique France.

Santé publique France

The challenge is to provide staff at Santé publique France with a framework for ethical questioning that responds to all six of the strategic challenges identified in the agency's work programme (Santé publique France, 2024). How can our actions remain effective when our professions are sometimes very different? In practical terms, how should we approach ethical questions on the ground? Whom should we consult? Whom should we call on? What types of support can be used to reduce the isolation of staff, while being aware of the agency's limited resources? These needs are

particularly acute for the regional offices, which operate in a variety of contexts that often require responsiveness. The concept of triangulation and the creation of shared discussion forums within the agency, which were discussed during the seminar, seem to be an appropriate way of supporting and guiding staff.

The ethical questions surrounding data processing go beyond the agency's remit, as they are shared by many partner institutions. Indeed, a major challenge is the production of valid public health indicators based on healthcare data, as the institution producing the indicator does not have control

over the quality of the data. In addition, a number of indicators are requested by authorities (regional health agencies, Directorate General for Health, ministries, etc.) outside the agency. Thus, the right level of reflection should be inter-institutional with the involvement of the concerned ministries and structures. Given the uncertainties inherent to the data used, a discussion forum between institutions is also desirable, although expressing doubts about the quality of the indicators produced, particularly in an emergency situation, is not necessarily accepted by the ministerial or political authorities.

Working with socially vulnerable groups means dealing with the ethical questions raised by their 'invisibilisation', as they are not covered by the major epidemiological surveys, the various health surveillance systems or the prevention services. Nevertheless, the risk of stigmatisation through the production of data and indicators specific to these populations must be taken into account. How can we strike a balance through reflection forums in order to reduce the moral bias (preconceptions) towards these populations and consider their concerns and needs, which may differ from the majority social norm? This balance necessarily requires including people from socially vulnerable populations in institutional governance bodies in order to co-construct knowledge and actions concerning them.

Other public health agencies in France and abroad

In the early 2010s, the Public Health Commission of the French National Authority for Health (HAS) began a process of reflection, which led to the publication of three methodological guides to help understand the economic, social and ethical aspects of its work (HAS, 2013). The challenges, particularly of an ethical nature, were considered during the scoping phase of the work and then, if necessary, addressed in the subsequent recommendation or evaluation carried out. The HAS is currently taking up these initiatives with a view to use the expertise in the humanities and social sciences (HSS) in an interdisciplinary perspective with the biomedical sciences. The complexity of the subjects treated, the situations of uncertainty and the need to ensure that the recommendations are considered more effectively mean that it is necessary to strengthen HSS expertise (acculturation, working methods, sharing of experience, etc.) and these new ways of working together.

Paradoxically, the fact that ANSES has multiple supervisory bodies means that it can demonstrate its independence more easily than other agencies. The overriding ethical issue is to create a shared, cross-disciplinary approach, given the diversity of committees and experts participating in them. This involves establishing a framework and rules for collective action within the expert committees and also for interaction between the agency and these groups. Each opinion is attributed a confidence level to qualify its uncertainty. This process also requires participants to adhere to shared values in terms of scientific rigour and transparency, which presuppose the transferability and accessibility of the methods used, as well as communication with stakeholders and society at large for a better exchange of views on the decisions taken by the relevant authorities.

In the USA, the CDC have created an ethics forum to develop skills and facilitate analysis and deliberation on ethical dilemmas. This forum is a place for learning through case studies and other structured approaches that, in addition to being documented, inform the ethical reflections and practices of professionals. Furthermore, the CDC ethics forum takes part in exercises to prepare for ethical conflicts in emergency situations. The agency's ambition is to help to shape ethical action in public health based on concrete cases and simulations.

In the Canadian experience, institutionalising ethics means prioritising an organisational culture that promotes an awareness of its utility at all hierarchical levels. The challenge is to build trust in the ethical process so that it is not perceived as a constraint by staff, instead being understood as a shared, cross-functional process for developing projects in the general interest. In fact, all the stages of a project are considered, not just the final stage of obtaining an opinion or authorisation. Ethics training seeks to help stakeholders to identify and verbalise ethical questions so that they can then reflect more deeply on solutions. This requires time for exchange and discussion, not to mention repeated training courses, because knowledge is acquired over time; staff mobility also needs to be taken into account. This repetition contributes to the acquisition of a common culture. The resources necessary are both human and financial, which marks a significant challenge for any public health organisation.

Regional Forums for Ethical Reflection (ERER)

The Regional Forums for Ethical Reflection (ERER), created by the French Bioethics Act of 2004, deal primarily with medical and clinical ethics. The COVID-19 pandemic and the crisis in the healthcare system have led to a shift towards public health ethics. In practical terms, the ERER facilitate public debates on health and research ethics and, more broadly, on digital health (Île-de-France ERER, 2017). The ERERs are involved in initial and continuing healthcare training to promote ethical reflection and analysis. They also monitor ethical practices via a cross-regional network of ethics advisors and have a number of partnerships, particularly with health democracy bodies. The ERER suffer from a lack of convergence regarding the different experiences and institutional questions, which would lead to a better understanding of the ethical issues of today and... tomorrow.

Representatives of civil society and associations

From the viewpoint of the Santé publique France Guidance and Dialogue Committee, one of the agency's difficulties in terms of collective ethics stems from the priority accorded to evidence (as in the case of scientific knowledge and its presupposed rigour), which is not the only component that needs to be considered when responding to the questions posed and identifying the issues to be addressed. Santé publique France staff need to be provided with a 'background in ethics and dialogue', which should start with an introductory booklet for new recruits. The aim is to empower staff and make them champions of the agency's values in the field and when in contact with stakeholders so that they

can make ad hoc decisions themselves without the need for institutional validation. In addition, it is important to emphasise the importance of looking at the problems specific to the field of environmental health, without letting them be clouded by the One Health concept. Finally, there is an ongoing debate about the agency's relationship with its supervisory body and its autonomy, as clarified by the State Council: 'While the agency serves the state and must respect the guidelines set by the supervisory body, it has the capacity to preserve its autonomy, particularly in the ethical and scientific domain'. Work must also be undertaken with the supervisory body to define the agency's values so that it can share and respect them. Preserving the agency's autonomy will not only help to appease internal relations but also to strengthen social trust in the agency.

While the role of citizens has become important in healthcare ethics, it remains marginal in public health. The role played by the relevant stakeholders is situated between two different poles: the population's acceptance of an intervention on the one hand and its co-construction on the other. Co-construction means recognising lay expertise. Within the agencies, its absence is not due to a lack of will but rather to a need to develop know-how. This also raises questions about the representation of healthcare system users, particularly vulnerable groups who need to be approached directly and about the ways of involving them. We need to incorporate a community health approach, which differs from one based on the 'patient expert'. Community health is based on the development of a collective voice, which is essential for public health ethics, particularly in the construction and implementation of prevention and health promotion initiatives, but also in restoring public confidence.

Session 4

Guidance for ethical analysis at Santé publique France:

An illustration of the pragmatic approach to ethics

Session moderated by Alain Fontaine and Michel Vernay

Benefits and limitations of public health ethical frameworks

Michel Désy, Quebec National Institute for Public Health (INSPQ), Canada; member of the Ethics and Professional Conduct Committee (CED), Santé publique France

The first ethical frameworks governing public health date back to the 2000s. Nancy Kass (2001) proposed a six-step framework for analysing an action: its goals, the effectiveness of the means chosen, its burdens, the minimisation of these burdens, its justice and the balance between benefits and burdens. While not all of the steps relate to ethics, such as the goals of the action, they refer to important underlying values and principles. This framework is seen as pragmatic due to its formalisation in terms of questions, which brings it closer to the concerns of public health professionals.

Although a framework is necessary to establish public health ethics, it is insufficient. It should be accompanied by organisational willingness, training and the provision of ethics services.

The Ross Upshur (2002) framework is based on principles (prevention of harm, least restrictive means, reciprocity and transparency). It focuses essentially on the tension between individual autonomy and the social values of solidarity and the common good. Its main idea is to limit the impact of public health decisions on individual freedoms as much as possible.

The <u>Childress et al.</u> (2002) framework is conceived as a set of moral considerations, some of which are found in other frameworks, and principles (effectiveness, proportionality, necessity, least harm and public justification) to approach these considerations. Here too there is an attempt to strike a balance between individual freedom and autonomy on the one hand and social values on the other.

The work undertaken by <u>Lisa Lee (2012)</u> distinguishes between theory- and practice-based frameworks. For example, the framework proposed by <u>Kenny et al. (2010)</u> is theoretical because it is based on a relational conception of autonomy. By contrast, other frameworks such as those of Kass and Childress are more practice-oriented and adopt the working language of professionals.

Brody et al. (2009) propose a classification with three framework categories: traditional, expansive and mixed. Traditional frameworks, such as that of Selgelid (2009), give priority to freedom, embodied, among others, by the principle of the least restrictive means. The so-called 'expansive' frameworks focus on equity and community, such as that of Baylis et al. (2008), which emphasises social justice. Mixed frameworks, such as that of Kass, attempt to reconcile these two options.

So what is the role of an ethical framework in public health? According to <u>Dawson (2009)</u>, it structures deliberation when decisions must be made, by making explicit the underlying values so that their impact can be assessed during implementation. It also allows us to build a bridge between theory and practice, and to assess the effectiveness and efficiency.

The traditional frameworks list various fundamental values in public health. They thus have an educational function for professionals who are unfamiliar with them. Nevertheless, they also have disadvantages, such as being difficult for profes-

sionals to use and arbitrarily giving more weight to some values than to others. Based on closed and non-exhaustive value systems, they may disregard certain values depending on the intervention and context.

Faced with these shortcomings, increasing attention is being paid to pragmatic frameworks, which aim to guide the thinking of professionals. That of <u>Grill & Dawson (2015)</u> suggests considering what may be justified by values, identifying alternatives, ranking them from best to worst, explaining why some are better than others and submitting the evaluation to the concerned institution. The Quebec Public Health Ethics Committee has favoured the use of a pragmatic framework for several years (CESP, 2015).

Although a framework is necessary to establish public health ethics, it is insufficient. It should be accompanied by organisational willingness, training and the provision of ethics services.

Many challenges exist. Public health ethics differs from research ethics: it is not intended to be prescriptive and rigid but rather to be integrated into the concrete reality of professional practice. The importance of ethical reflection must be balanced against the primacy given by professionals to scientific aspects. The aims of public health, such as maximising collective health, also need to be addressed through the specific analysis of populations and the particularities of the context. Finally, ethical reflection is sometimes timeconsuming and complex, requiring regular adjustments, particularly in emergency situations.

This means that we need to adapt to the needs of professionals. It is also important to work with professionals to identify persistent problems, such as those raised when investigating clusters (spatiotemporal aggregates) of pathologies. Finally, it is essential to continually raise awareness among professionals.



Establishing guidance for public health ethical analysis at Santé publique France

Martine Ledrans, Santé publique France

Reflections on ethics within Santé publique France have led to the development of a reference framework for identifying and dealing with ethical questions on a joint basis. The document 'Repères pour l'analyse éthique à Santé publique France' ('Guidance for Ethical Analysis at Santé publique France') (Ledrans et al., 2024) responds to this need. It was drawn up following a literature review, consultation with other institutions, consultation with volunteer professionals from the agency, two workshops with staff from the agency and support from the agency's Ethics and Professional Conduct Committee (CED). Feedback from the Public Health Ethics seminar was given priority, particularly through the presentation and discussion of the document in the first preparatory workshop and then at the summary seminar.

The aim of this approach is to clarify the choices made by reviewing the 'standards' and the values at stake and by explaining the ethical arguments behind the choices made, with a view to foster openness and dialogue: 'Building on action rather than simply transmitting knowledge'.

This document sets out the values that can be used to support the ethical approach in public health and the analysis process used to support the development of the agency's projects. Designed as an aid and support and not as a prescriptive element of practice, it is intended to be evaluated and updated according to its use by Santé publique France staff.

The approach is based on reflective and deliberative analysis that seeks modes of action to 'do the right thing' or 'act for the best' in the general interest. The aim is to give concrete expression to the values considered to be priorities in a given situation and context. The aim of this approach is to clarify the choices made by reviewing the 'standards' and the values at stake and by explaining the ethical arguments behind the choices made, with a view to foster openness and dialogue: 'Building on action rather than simply transmitting knowledge'.

This process has four phases:

- 1. The first phase, the preparatory phase, describes the key elements of the project (problem, context, objectives, intervention options, resources, etc.) and the challenges it faces, particularly in health, social, economic and political terms. It specifies the applicable standards and rules, particularly from a legal viewpoint, and identifies the parties concerned (populations, local authorities, institutions, etc.), as well as the foreseeable consequences of the project for each of them. During this phase, we will also try to understand the ethical preoccupations already identified by the concerned parties and the literature.
- 2. The second identifies the ethical questions, dilemmas or challenges by examining the values associated with the purposes of the project and its consequences, as well as those underlying the standards or rules that govern it. The ethical questions raised are then formulated, particularly with regard to the tensions

- generated by the project when implemented. If no ethical questioning is identified, the analysis stops at this stage.
- 3. The third stage is to identify the priority values associated with the ethical questioning or challenges, and to evaluate the possible actions to address them. This involves analysing the overlaps and tensions between values, ranking the benefits and challenges according to the possible options and taking into account the viewpoints of the concerned parties.
- 4. The fourth stage, the decision stage, identifies the option that best consolidates the priority values and minimises the impact on the other values in a given situation, while making the arguments explicit. Then, in a reflective manner, we take 'a step back' to assess the reasonableness and legitimacy of the proposed option.

A number of key values have been identified and are cited in the 'Guidance' document. They do not constitute a closed system specific to the agency. They are instead broad and refer to the practice of public health in a societal context.

The document makes practical proposals for conducting ethical analyses of the agency's projects. These include the following:

- Starting ethical reflections from the project design stage in order to identify the potential challenges and conflicts with regard to values, which will need to be integrated into the construction and evaluation of the project, as well as during the implementation stage, and paying attention to signals that may point towards an unanticipated ethical challenge.
- Conducting the first two phases with only the project team and, in the event of ethical questioning, calling on a larger think tank for the third and fourth phases, depending on the questions and context, while specifying the time frame, any work to be carried out, stakeholder involvement, consultation of the CED, etc.

- Paying attention to complex situations such as disagreements within the think tank or teams, stakeholder refusal or hostility, the need to consult the population, etc. In such cases, consider using the expertise of the CED, an internal ethics advisor and/or external resources.
- Writing up the process to learn from the shared experience.

The levers and conditions for success will be based on multiple factors: commitment of the agency's entities, dissemination, awareness, support, facilitation, internal communication, reinforcement of ethical competences and understanding of the socioprofessional context.



Round table: What are the prospects for integrating ethical questioning into public health activities?

Santé publique France wishes to develop its capacity to integrate and address ethical questioning when implementing its missions and programmes. This approach is notably reflected in the adoption and sharing of an ethical framework in public health. Following an introduction on the ethical frameworks used in public health and the presentation of the 'Guidance for Ethical Analysis' document developed by Santé publique France, this round table aimed to outline the perspectives.

Environmental health and occupational health

Mélina Le Barbier,

Environmental and Occupational Health Department, Santé publique France

The 'Guidance for Ethical Analysis' document is a very useful tool, as it helps staff to integrate ethical considerations into the design and implementation of environmental and occupational health programmes and projects. Staff reflect on ethics in an informal and empirical way, without necessarily being aware of it. This tool will enable them to formalise their ideas and integrate them more effectively into their practice. The Ethics and Professional Conduct Committee (CED) has been asked to help to set out this four-step process, which is described in the 'Guidance' document. Moving towards the internal integration of ethical questioning is a journey that will allow future actions to be based on structured and opposable ethical choices; in this respect, the CED acts as a support and advisory body in public health ethics. This tool, which can be used to identify and formulate ethical questions, nevertheless requires support in order to deepen value-based analysis and take it into account when implementing actions. Considering that the population's values in their life context is an important aspect of environmental health, it cannot be improvised and involves building support that requires competences in ethics. Beyond the role of the CED,

which remains central, it will be necessary to create shared spaces to build a common culture of reflection. The occupational health dimension raises specific questions that differ from those encountered in the field of environmental health. Finally, how can we, from the ethical viewpoint, question old systems that have been in place for years and are still operational?

Application to a community survey on perceived health

Christophe Perrey, Regions Department, Santé publique France

The 'Guidance' document is structured in four phases. Phases 1 and 2 can be easily accessed and appropriated by staff who are not necessarily trained in ethics. However, as mentioned by other participants, Phases 3 and 4 require support, which is to be clarified at a later date. As a test case, it was applied retrospectively to a project evaluating self-reported health (health as perceived by individuals in a given context), a subject that is a frequent source of conflict. The benefit of the 'Guidance document' lies primarily in the fact that it includes all issues in the ethical examination and that the reflection can be exhausted by formalising it in writing. In particular, it requires contextual self-questioning about the purpose of one's professional practice (or work) and

its utility. This is an important dimension because, unlike in clinical practice, the results of public health interventions are not immediately visible. Its successful implementation will require the motivation of the internal staff, which will facilitate the institutional support provided by the agency's general management and other departments. Identifying mediators and setting up a think tank and forums for reflection can also help to achieve this. These think tanks can be given themes, such as the issue of autonomy in relation to guardianship, the sharing of values to restore trust or the response to epidemics. The difficulty lies in our expectations of our staff. Competences in public health ethics will need to be added to their core professional skills in a context of limited resources.

Application to a survey on parenthood

Maud Gorza, Prevention and Health Promotion Department, Santé publique France

We were able to experiment with the use of the 'Guidance' document during a survey of parents of young children to explore the determinants and experiences of parenting, a project that deals with very sensitive subjects - particularly the adverse elements of parents' lives. This structured document made it possible to evaluate the comprehensiveness of the ethical analysis conducted and to devote time to reflect on the conceptual framework for ethical analysis. It also made it possible to summarise the questions with an appropriate and shared vocabulary. It is important that this tool is disseminated internally and shared via the agency's departments, and that staff are given time to familiarise themselves with it. While it is necessary to formalise the application of this process in writing, it must be recognised that sometimes there is insufficient time to do so.

Importance of context: Santé publique France's Regional Office in Mayotte

Hassani Youssouf, Mayotte Regional Office, Santé publique France

The Mayotte Regional Office operates in a particularly complex public health context. The territory is facing a dramatic water shortage, with major rationing (cuts of up to 54 hours) to ensure continuity until the next rainy season. This occurs against a backdrop of uncontrolled illegal immigration. The Mayotte Regional Office has been mobilised to evaluate the health impacts of this water shortage. Conventional surveillance based on healthcare use excludes the most vulnerable populations, particularly illegal immigrants. To counter this, the Regional Office has deployed community-based surveillance using associations or mediators based in vulnerable communities, the majority of whom are illegal immigrants. The identification of health problems, particularly epidemics, through this community surveillance does not, however, resolve the lack of access to care for the identified patients (fear of the border police, mistrust among the local Mahoran population of migrants from neighbouring Comoros islands, etc.). Communicating the data and warning signs thus generated and implementing legitimate targeted actions to reduce the risk to the concerned communities and beyond have become very complex and operationally difficult tasks. For the agency's staff, the ethical questioning could be summed up as follows: 'How can we protect the most vulnerable populations in such a context?' This goes beyond the scope of the 'Guidance' document, not least because of the underlying political dimensions.

Outlook from the Scientific and International Division

Sophie Legond, Scientific and International Department, Santé publique France

The challenge for this cross-functional department is to facilitate the establishment of an ethical approach within the agency and its operational use by the different teams. The aim is to continue the efforts made as part of the ethics projects conducted over the last two years to disseminate and instil this reflection into the work of staff, right down to the field level, where needs arise with regard to the ethical questions encountered. Several avenues are currently being explored. Firstly, the 'Guidance' document will be promoted and disseminated via the agency's intranet along with the documents produced as part of the preparatory workshops and this summary seminar. After applying the 'Guidance' document in the field for two years, it is planned to review the experience with staff and, if necessary, adapt it to the agency's practice. Internal think tanks and experience-sharing groups, which are frequently cited, are certainly worth considering, although their establishment comes up against the limited agency resources. The use of outside help is another alternative to consider. New awareness-raising initiatives need to be undertaken within the agency, including the development of case studies, which will be facilitated by the 'Guidance' document. External training will help the relevant staff to expand their knowledge and especially their know-how in a professional context. A partnership with a university team specialising in ethics could also be envisaged to support the agency in establishing this ethical approach within its public health practice. The challenge is to operationally address the very diverse ethical questions raised in the public health practices of our staff and, in particular, to identify what can be treated at the team level and what needs to be explored in greater depth with specific expertise in ethics or be handled by the Ethics and Professional Conduct Committee (CED). The relationship between the CED and the Guidance and Dialogue Committee (COD) should also be considered. The ethical dimension of public health is included in the 2024-2028 Contract of

Objectives and Performance with the Ministry of Health (Santé publique France, 2024), which, by its very nature, guarantees its long-term establishment and indicates strong institutional support.

A reference framework in ethics is necessary but insufficient: Experience of the Public Health Agency of Canada

Mireille Lacroix, Public Health Agency of Canada (PHAC), Canada

The Public Health Agency of Canada has an ethical framework with a similar approach to that presented in the 'Guidance' document. The agency is currently renewing this framework and the following question has arisen: for whom is it intended? The first framework was aimed at agency staff so that they could start their own ethical analysis. Today, its scope is being questioned. Should it be aimed at the agency's ethics committee? Or should it be shared with the population to offer a clearer idea of how the agency approaches ethics in public health? The response will have a major impact on the content and form of the document. For example, a few years ago, the agency provided support for this framework to the Emergency Medical Reserve, which manages the medical equipment necessary for public health emergencies. The reserve team had contacted the Ethics Committee regarding a pharmaceutical product that was not available in Canada. Requests made to the team for the prophylactic use of this product gave rise to various questions: the reason for the request was not completely in line with the product indications; limited quantities of the product were held in reserve; its expiry date was unknown; and its inclusion in the reserve could lead to wastage. This dilemma was addressed through the ethical framework, with the development of a pre-established analysis grid and support in the form of work sessions. The challenges were identified collectively, as were the elements for modulating the response to these questions of an ethical nature. This experience showed that beyond the ethical framework, it is important for staff to be competent in ethics to support public health programmes. Using the framework in isolation can be problematic, particularly in terms of how the 'ethical'

questions and values to be analysed are defined. It also showed us the importance of multidisciplinarity. The way in which the reflection was structured was greatly appreciated, enabling us to clarify the issues, explore them in greater depth and justify the choices made in a satisfactory way. Although this exercise is time-consuming, the staff's capacities develop with the support provided, and this investment saves time when responding to any new questions that arise. While the need for an easily accessible tool is legitimate and must be taken into account, the complexity of ethical questions requires analytical reflection and appropriate deliberation, hence the necessity for structured, institutionalised support.

Outlook

Paving the way for ethical questioning at Santé publique France

This seminar reflects the preoccupation of Santé publique France for over ten years (and previously at the Institute for Health Monitoring [INVS] and Institute for Prevention and Health Education [INPES]) to take better account of the ethical dimensions of its work. The Ethics and Professional Conduct Committee (CED) has always been supportive during this process. It was important for the CED, which became one of the agency's governance bodies in 2016, to integrate ethical reflection specific to public health into its activities of surveillance, surveys, expertise, prevention, health promotion, and so on, which, by nature, are population-based.

Ethical reflection and the formalisation of ethical questioning may already exist within the agency, but they are far from systematic and explicit in our public health programmes and actions. Sharing our experiences, both in France and in its regional areas, including overseas territories, was essential to collectively understand the ethical questions and dilemmas encountered in our practice. This summary seminar drew on reports from the CED, three reflective workshops including

To reiterate, this summary seminar represents a milestone in the development of a public health ethics approach at Santé publique France in order better carry out its missions and better advise public health decision-makers to protect and improve the health of the population.

case studies, one internal consultation with staff. one external consultation with public health professionals, Opinion 137 'Ethics and Public Health' of the National Advisory Committee on Ethics (CCNE) and the experience of other agencies in France and abroad. From a pragmatic perspective, we aimed to understand each other (what do we mean when we talk about public health ethics?), and to work with the CED and other French organisations, particularly health agencies, to develop shared (at least known) foundations within the agency. With this in mind, the 'Guidance for Ethical Analysis in Public Health' document, validated by the CED and presented in the last session of this seminar, represents a major step forward in terms of establishing an ethical approach.

To reiterate, this summary seminar represents a milestone in the development of a public health ethical approach at Santé publique France in order to improve how it conducts its missions and how it advises public health decision-makers in protecting and improving the health of the population. By summarising the work carried out, this seminar aims to map out the path and conditions for integrating ethical questioning into the workings of the agency, thus echoing the 'institutionalisation' mentioned by Lisa Lee in her presentation.

It is likewise vital to share our experiences and include the concerned institutions, agencies and bodies in the construction and pragmatic application of public health ethics in order to increase our collective capacity, including the development of appropriate staff training.

In conclusion, I would like to end with the perspectives for Santé publique France, which are centred around three areas of action:

 Integrating ethical questioning and reflection in public health into the agency's activities and programmes. This means developing a common culture of public health ethics as well as sharing that culture and its challenges with other institutions (particularly agencies) by establishing interface mechanisms with the CCNE, the French Regional Forums for Ethical Reflection (ERER) and the National Conference of Regional Forums for Ethical Reflection (CNERER).

- Raising awareness, increasing training and supporting staff, which represent an internal challenge for the dissemination of a collective and shared culture of ethics in public health and the appropriation of an ethical approach by staff at Santé publique France. In particular, this means providing tools and support for the establishment of the ethical approach, starting with the 'Guidance for Ethical Analysis at Santé publique France'. Awareness-raising and training at internal level are major challenges. As Laurent Chambaud of the CCNE pointed out, the development of academic and professional training in public health ethics is a key issue for the coming years.
- Adding value internally and externally by sharing experiences (experiential and academic), noting in particular that the approach and experience of Santé publique France are quite unique, and emphasising the quality of the contributions made by the participants and foreign colleagues gathered here today.

These broad guidelines will be clarified in the coming months.

The quality and relevance of the work carried out at Santé publique France in support of decision-making and public policy are also based on a respect for ethical values and principles. As a result, the ethical questioning in public health raised by this seminar will be included in the draft 2024–2028 Contract of Objectives and Performance (COP) between Santé publique France and the French Ministry of Health and Prevention in Area 4 'An efficient and responsible agency', Orientation 2 'Ensure compliance with principles and rules of professional conduct and integrate the public health ethics dimension into the activities and projects of the agency'.

The inclusion of ethical questioning in the COP is the first step towards its institutionalisation and owes a great deal to the work carried out as part of this seminar, which I am pleased to conclude.

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Ethics applied to public health

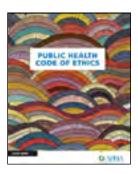


Diagram based on the US Public Health Code of Ethics ($\underline{APHA~2019}$) and the article 'Ethical competencies for public health personnel' (Lee 2018)

6 core values
Professionalism and trust
Health and safety
Health justice and equity
Interdependence and solidarity
Human rights and civil liberties
Inclusivity and engagement

8 considérations
Permissability
Respect
Reciprocity
Effectiveness
Responsible use of scarce resources
Proportionality
Accountabilty transparency
Public participation

4 steps for ethical decision making	Method
 Ildentify ethical dimensions Articulate ethical dimensions and dilemmas Deliberate a path forward (evidence, laws, values and lived experience) 	Relective and participatoryMultidimensionalOpen to revision
Implement and evaluate	

Participants

Introduction

Anne-Catherine Viso

Anne-Catherine Viso is currently the Director of the Scientific and International Department at Santé publique France. After a PhD in Toxicology and ten years in charge of European affairs relating to water management regulations in the private sector, she joined the national health agency twenty years ago. Since the 2010s, she has taken an interest in ethical questions in public health following encounters with various foreign agencies, particularly the Centers for Disease Control (USA) and the Quebec National Institute for Public Health. These experiences subsequently led to her proposal to set up an Ethics and Professional Conduct Committee at the Institute for Health Monitoring (InVS), which was subsequently integrated into the governance of Santé publique France.

Session 1

Lisa Lee

Lisa M. Lee (PhD, MA, MS) is Associate Vice-President for Research and Innovation and Director of Scholarly Integrity and Research Compliance at Virginia Tech (USA). She is a professor in the Department of Population Health Sciences. From 2017 to 2018, she served as the Inaugural Chief of Bioethics at Walter Reed Army Institute of Research. From 2012 to 2017, she was Executive Director of the Presidential Commission for the Study of Bioethical Issues set up by President Barack Obama. For over twenty-five years, she has worked in public health and ethics at local, state and federal levels. She received her PhD from Johns Hopkins University School of Public Health, and also holds a Masters in Educational Psychology and a Masters in Bioethics. She is an expert in infectious diseases epidemiology, a bioethicist and an ethics educator.

John Kinsman

John Kinsman, who holds a PhD in Medical Anthropology, joined the European Centre for Disease Prevention and Control (ECDC) in early 2019 to work on questions relating to social and behavioural changes in relation to vaccination and the prevention of antibiotic resistance. During the COVID-19 pandemic, his work focused on responding to pandemic fatigue within the population, supporting socially vulnerable populations, preparing and supporting the implementation of COVID-19 vaccines and countering online vaccine misinformation. He now supports the ECDC Prevention Framework, which includes a community of practice for EU social and behavioural

science researchers working on communicable disease prevention. He has been working on social and behaviour change initiatives since 1996 – in Africa, Asia, Latin America and the EU – on a wide range of questions, including the social determinants of health, health systems, public health emergency preparedness, antibiotic resistance and vaccine acceptance and uptake.

Laurent Chambaud

A doctor of medicine, Laurent Chambaud is a public health physician and General Inspector of Social Affairs. Now retired, he is a member of the French National Advisory Committee on Ethics (CCNE). He was Director of the French School of Public Health (EHESP) from 2013 to 2022. He was adviser to the Minister for Social Affairs and Health, Marisol Touraine, with responsibility for organising and coordinating public health policy and health safety. After working at the Inspectorate General of Social Affairs from 2006 to 2010, Chambaud was Director of Public Health at the Ile-de-France Regional Health Agency. He previously headed the Franche-Comté Regional Health and Social Affairs Directorate (2002–2006), and the Mayenne DDASS from 2018 to 2002.

Session 2

Jean-Claude Desenclos

A doctor of medicine and science, Jean-Claude Desenclos specialises in epidemiology and public health. He devoted several years to general medicine followed by humanitarianism and public health abroad. After three years at the Centers for Disease Control and Prevention (Atlanta, USA), he joined, at its creation, France's National Public Health Network, which later became the Institute for Health Monitoring (InVS) then Santé publique France. In 2008, he became Scientific Director of Santé publique France, a position he held until his retirement late 2020. Accredited to supervise public health research, he is affiliated with the Doctoral School of Public Health, where he supervised a dozen PhD students in epidemiology. Since 2021, he has continued to contribute to the work of Santé Publique France on a part-time basis. It was in this context that he coordinated and facilitated the work of the Santé publique France Public Health Ethics seminar.

Marc-Karim Bendiane

Marc-Karim Bendiane is a sociologist of religion who became a doctor in Public Health, Epidemiology and Clinical Research. Since 1994, he has worked both in tacademia and as a consultant (evaluating health policies and political decision support). He is affiliated with the Joint Research Unit 1252 Economic and Social Sciences of Health and Medical Information Processing (SESSTIM) at Aix-Marseille University. He has been tasked by Santé publique France, as part of the provision of a service, to provide support for the conduct of the Public Health Ethics seminar, including the consultation of a panel of around forty professionals and experts in public health or ethics from outside Santé publique France.

Clarisse Vignollet

Clarisse Vignollet is currently a Masters 2 student in Public Health at the University of Bordeaux/ISPED and is carrying out her work placement at Santé publique France. In 2022–2023, as part of a Political Science Masters in Social Issues and Health Policy at Jean Monnet University-Department of Political and Territorial Studies in Saint Etienne, she completed a work placement at Santé publique France as part of the reflective seminar on the establishment of a pragmatic ethical approach in public health practice. She performed and analysed a sociological survey using semi-structured interviews of a diverse sample of Santé publique France staff on the challenges, constraints and levers involved in integrating ethical questioning into the activities and missions of a public health agency.

Nicolas Lechopier [moderator]

Nicolas Lechopier is a lecturer in philosophy, epistemology and ethics at the Lyon-Est Faculty of Medicine (Claude Bernard Lyon 1 University). His research focuses on the social, ethical and political questions raised by public health programmes. In particular, he has explored the issue of personal data in epidemiological research, the participation of affected individuals in environmental health research, the forms of surveillance in medicine and public health, the tensions associated with cancer screening and the epistemology of interventional research in population health. He teaches humanities and social sciences to medical students. He is a member of the Ethics and Professional Conduct Committee of Santé publique France.

Session 3

Grégory Aiguier

Grégory Aiguier holds a PhD in Medical Sciences and is a teacher-researcher/lecturer at the Centre for Medical Ethics - CEM (EA 7446 'Ethics') at the Université Catholique de Lille, where he is deputy director. He is also responsible for educational coordination and innovation within the CEM and the 'Ethics' (EA 7446) and 'Taking Care, Inclusion, Society' (PSIS) research units. He is President of the Ethics and Professional Conduct Committee of Santé publique France.

Enguerrand du Roscoät [moderator]

Enguerrand du Roscoät is a psychologist trained in social psychology. He has extensive experience in the field of addictions (alcohol, tobacco, illicit drugs, gambling) and mental health (depression, suicide, skills development, sleep). He is head of the Methodology Unit of the Prevention and Health Promotion Division of Santé Publique France.

Session 4

Michel Désy

Michel Désy has been a specialist ethics advisor at the Quebec National Institute for Public Health since 2010. He has been secretary of the Public Health Ethics Committee since 2018. He was also a researcher at the Montreal Public Health Directorate from 2002 to 2008. Following his PhD in Philosophy from the University of Montreal, he completed a postdoctoral internship on the ethical dimensions of public policies and their impact on population health at the Ethics Research Centre of the same university, in partnership with the National Collaborating Centre for Healthy Public Policy. He has also been a clinical lecturer at the University of Montreal School of Public Health since 2016.

Martine Ledrans

Martine Ledrans is a retired epidemiologist specialising in environmental risks and exposures. She was director of the Environmental Health Department at the Institute for Health Monitoring (InVS) and Head of the Antilles-French Guiana Regional Office of the InVS. At Santé publique France, she leads the 'Guidance for ethical analysis' project.

Alain Fontaine [moderator]

Alain Fontaine is a doctor of medicine and holds a PhD in Health Policy and Administration (Chapel Hill, USA). He was a hospital practitioner from 1992 to 2001. He then continued his career at France's Directorate General for Health (DGS), working on health and research policies and strategies. He has also coordinated the writing of documents on the missions of the High Council of Public Health and the Health Expertise Charter, and contributed to the development of public health research, to the organisation of the production and use of health data and indicators at national and European levels, and to the reflection of the National Advisory Committee on Ethics on the ethical challenges of the use of digital technology in health. He is a member of the Ethics and Professional Conduct Committee of Santé publique France.

Michel Vernay [moderator]

Michel Vernay is an epidemiologist (PhD in Population Genetics) specialising in the burden of chronic diseases and their prevention. He was head of the Santé publique France unit in the Grand Est, particularly during the COVID-19 epidemic in that region. He is currently director of the Non-Communicable Diseases and Trauma Department of Santé Publique France.

Outlook

Caroline Semaille

Caroline Semaille was appointed chief executive of Santé publique France on 23 February 2023. A hospital doctor in public health and infectious diseases specialist with accreditation to supervise research, she began by devoting her career to the problems of infectious diseases, particularly the fight against HIV/AIDS, through prevention projects, early treatment provision and humanitarian missions. She then spent more than twenty years working for French health agencies (Institute for Health Monitoring [InVS], National Agency for Medicines and Health Products Safety [ANSM], National Agency for Food, Environmental and Occupational Health and Safety [ANSES]). Over the course of her career, she has contributed to the management of several international health crises, such as SARS, H1N1, MERS-CoV, Ebola and most recently COVID-19 during her time at Reacting/INSERM in March-April 2020.

Organisation Committee

A team from the Santé publique France Scientific and International Department, with the support of a Masters 2 student and the services of a consultancy firm, drew up the scientific programme, facilitated and led the seminar and wrote the 'Insights' document devoted to it. The team was coordinated and facilitated by a specialist in epidemiology and public health, who was the former Scientific Director of Santé publique France.

- Jean-Claude Desenclos, Scientific Director of Santé publique France (2008–2020)
- Anne-Catherine Viso, Director of the Scientific and International Department, Santé publique France
- Sophie Legond, Ethics and Professional Conduct Coordinator, Santé publique France
- Catherine Buisson, Ethics Action Plan Coordinator, Santé publique France

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