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The Bioethics and Ethics of Science Section reflects the priority UNESCO gives to ethics of science and technology, with emphasis on bioethics. One objective of the Organization is to promote principles and ethical norms to guide scientific and technological development and social transformation.

Activities of the Section include providing support for Member States of UNESCO that are planning to develop activities in the field of ethics of science and technology, such as teaching programmes, national ethics/bioethics committees, conferences and UNESCO Chairs.

The Section also ensures the executive secretariat for three international ethics bodies, namely the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST), the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC).

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Bioethics Committees and Public Engagement

UNITED NATIONS EDUCATIONAL, SCIENTIFIC AND CULTURAL ORGANIZATION
DIVISION OF ETHICS OF SCIENCE AND TECHNOLOGY
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FOREWORD

UNESCO’s Bioethics and Ethics of Science and Technology Programme presents the last two guides in a series of tools intended, mainly, for National Bioethics Committees.

The Guide on Bioethics Committees and Public Policy (Guide 4) and the Guide on Bioethics Committees and Public Engagement (Guide 5), can be used independently, but have complementary links.

They constitute a continuation of earlier publications:

Guide 1 presents the different forms and objectives of the various Bioethics Committees:

1. Policy-making and/or advisory body: to establish sound science and health policies for Member States’ citizens.
2. Health Professional Association Committee: to establish sound professional practices for patient care.
3. Health care / Hospital Ethics Committee: to improve patient-centred care.
4. Research Ethics Committee: to protect human research participants while acquiring generalizable biological/biomedical/behavioural and epistemological knowledge

Guide 2 provides guidance to chairpersons and members of all types of Bioethics Committees on internal procedures and policies to consider and adopt in order to fulfil their mandate.

Guide 3 provides guidance to chairpersons and members to pursue their long-term educational duty to achieve the goal of compassionate understanding and decision-making in the face of complex bioethical issues and dilemmas.

Bioethics Committees have worked to become instruments of fairness and justice, to enhance human values, to recognize cultural differences, and to protect human rights.

With Guides 4 and 5, we now have guidance intended to assist Bioethics Committees in their efforts to promote public debate and engagement in order to raise awareness among civil society, and to take its voice duly into account when developing policies. This is essential because we live in a world where individuals (and communities) exercise their citizenship not only by voting, but also by playing an active role in the decisions governments make in areas of great concern to them. This is particularly true in bioethics and the ethics of science and technology.
Advances in biotechnology, nanotechnology, neurotechnology and information technology are developing rapidly and are becoming very difficult to understand. Moreover, they are now converging and combining in new ways, posing new challenges to managing their highly uncertain consequences. The undeniable impact that they have on health (including predictive and preventive interventions), life (including potential enhancement), and on many other areas and activities, such as leisure, agriculture or the environment, is one of the reasons why they are known as disruptive, transformative and frontier technologies. In addition, they pose new social, ethical, political, economic and environmental challenges and create the need for a different and holistic approach.

The social context in which biotechnology is emerging plays an important role in its significance. That is why it is so important to engage society as a whole in addressing its development concerns and priorities. Civic process and social debate should support the democratization of decision-making procedures and ensure that the diverse perspectives of men, women, youth, the elderly, various ethnic groups, among others, are specifically taken into account and that no one is left behind when it comes to benefiting from the fruits of science and technology.

In October 2005, the General Conference of UNESCO adopted by acclamation the Universal Declaration on Bioethics and Human Rights (UDBHR). More than 193 Member States have committed themselves to respecting and applying the fundamental principles of bioethics, which they agreed upon and integrated into a single text.

In the Preamble, the UDBHR states:

‘Convinced that moral sensitivity and ethical reflection should be an integral part of the process of scientific and technological developments and that bioethics should play a predominant role in the choices that need to be made concerning issue arising from such developments…’

In addition, Article 19 on ‘Ethic committees’ reads:

‘Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to:

a. assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings;

b. provide advice on ethical problems in clinical settings;
c. assess scientific and technological developments, formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration;

d. foster debate, education and public awareness of, and engagement in, bioethics.’

There are different ways of conducting public debate and engaging the public in policy-making, but there is no doubt that it is necessary to do so. Bioethics Committees play a key role in promoting these processes and support governments in their role of providing accurate information and maintaining constant and transparent communication with the public, so that society understands and endorses the policies adopted, whether or not they agree with them.

The present Guides are intended to be a source of inspiration and of practical assistance, and provide examples from Bioethics Committees in various countries on how NBCs have approached these tasks. UNESCO’s Bioethics Programme is also ready to provide additional support to any committees that may request it.

We are grateful to Dr Jan Helge Solbakk, Professor of Bioethics and Medical Ethics; Dr Georgios Papanagnou, Researcher and Policy Advisor; and Dr Ingrid Callies, Legal and Ethics Advisor, for their support, expertise and assistance in the preparation and development of these guides.

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INTRODUCTION

The rapid expansion of knowledge in every field of inquiry and especially in the life and biological sciences changes profoundly the way we live. These changes are highly contingent on the accelerated mode of technological progress, which is a pervasive feature of modern societies. Biotechnological advancement continues to yield innovative applications in a vast array of scientific fields: biofuels, synthetic biology, nanotechnology, gene editing technology, artificial intelligence, human and animal cloning, cisgenics, regenerative medicine, biobanks, together with new diagnostics, preventive and therapeutic interventions are some of the most exciting and debated subjects in 21st-century life sciences. Nevertheless, as traditions are decentred and familiar routines are phased out, the modern technological developments are often accompanied by anxiety. While biotechnology mostly inspires optimistic attitudes with regard to its potential to better human life, ambivalent stances are also common. In consistence with the modern condition of perceiving change as both danger and opportunity, innovation in the biological and life sciences is negotiated amidst several tensions. As changes in practice occur in dialectical relationship with changes in values, these tensions often manifest in debates over the moral and ethical dimensions of our new capabilities. Bioethics is the interdisciplinary field that deals with the dilemmas that arise in the context of novel practices in the wider biological field. It necessarily rests upon the understanding of technology as socially constructed: it shapes and at the same time, it is being shaped by our own values and attitudes.

Bioethics indeed examines the ethical issues raised by the life sciences, their technologies and applications, as well as medicine and health policy. It expands across more than one scientific fields as it delves into matters that touch upon all areas that are affected by the scientific developments; it looks equally at their social, legal and environmental aspects. This diversity defines bioethics broadly to include not only the health sciences, but also the natural, social and human sciences. Nevertheless, reflection on bioethical issues is no longer the exclusive concern of specialists, scientists, medical professionals or policymakers. Indeed, these are the very people that now carry the responsibility to open up the dialogue on these issues to the public. This is warranted by the nature of the bioethical dilemmas: they relate to public health, to matters of dealing with disease, disability, death or suffering that are part of our shared human experience. As much as these can be addressed on a national or even regional level, the processes of globalization increasingly determine them. The implications of globalization with regard to bioethics can be observed in the cases where sponsors carry out clinical trials in countries with economies in transition and developing economies without applying the same standards of informed
consent and risk assessment as in countries with developed economies, or without sharing the outcomes of their research with the local population. Of important moral concern are also the cases where patients die because of lack of resources (e.g. medication for HIV/AIDS, malaria and tuberculosis) that are available in other countries. The global reach of modern science calls for a global approach to bioethics, and this understanding guides the UNESCO’s Assisting Bioethics Committees program.

For UNESCO, Bioethics must become more than ever everyone’s business. The appreciation of the common heritage of humankind, together with a focus on the social good, construct bioethics as a pluralistic and inclusive global project. The National Bioethics Committees (NBCs) are instrumental in enforcing the ideals of participation in their local contexts, and more widely as they jointly form international networks. Their normative ideals are grounded on the framework constituted by the relevant Declarations of UNESCO Member States: the *Universal Declaration on the Human Genome and Human Rights*1, in 1997; the *International Declaration on Human Genetic Data*2, in 2003; the *Universal Declaration on Bioethics and Human Rights*3 (UDBHR), in 2005; and, lastly, the *Declaration of Ethical Principles in relation to Climate Change*4, in 2017. On the pragmatic level, they operate on the shared norms, rules and practices mostly documented in the previous Guides for NBCs. NBCs coordinate the reflection on and the application of bioethics, including environmental, social, multicultural and gender considerations and integrating the local demands with concrete solutions in countries with varying levels of economy. In other words, it is the goal of NBCs to empower citizens of the world to not only take stock of the effects of scientific progress in their lives, but also to facilitate their involvement in the development of health and research policies and its accompanying ethical issues, so that they receive its benefits.

This Guide further discusses the relationship between Bioethics, NBCs and the global publics in the following section. In Part 1, Bioethics is constructed in terms of its responsibility to fighting inequality and promoting social justice. These are fundamental values for NBCs and can be found in the five Declarations. Part 2 looks at the theoretical grounding that informs the functions of NBCs. It discusses the relationship between the model of deliberative democracy and Bioethics, and looks at their shared aspirations when it comes to their public role. To this end, the conditions and purposes of deliberation are discussed, as well as how the concepts of public sphere and consensus fit in NBCs procedures. Part 3 provides a toolbox, and Part 4 gives examples of NBCs and public engagement.

1 https://unesdoc.unesco.org/ark:/48223/pf0000122990
2 https://unesdoc.unesco.org/ark:/48223/pf0000136112
3 https://unesdoc.unesco.org/ark:/48223/pf0000146180
4 https://unesdoc.unesco.org/ark:/48223/pf0000260129
PART I

THE NEED FOR PUBLIC BIOETHICS

1. Global Bioethics for Equality and Social Justice

The institutionalization of bioethics, in which UNESCO has played a pivotal role, signified a turn of the field from the academia towards the political. NBCs are agents that influence policy-making; they instigate and participate in the public debate around relevant issues. Their activities correspond to the priorities that UNESCO Member States have set for the organization when it comes to ethics: a) standard-setting: developing normative frameworks that will guide policy-making (see Guide 4), b) capacity-building: enhancing the infrastructure of States so that they are prepared to cope with the issues emerging from techno-scientific applications, and c) awareness raising: supporting public dialogue so that citizens are informed of their moral choices vis-à-vis the advances in biological sciences. The scope of these activities is international, and this makes bioethics a global project. UNESCO’s Bioethics Programme promotes a broad view of bioethics that brings together individual, social and environmental concerns. In this sense, it performs the idea of global bioethics, coined by Van Rensselaer Potter in the late 80s. According to this vision, social responsibility, benefit sharing and protection of future generations underlie the normative framework for a truly global bioethics.

The global reach of life sciences and their applications necessitates the public accountability of bioethics. With the expansion of globalizing processes, the emerging moral dilemmas that affect the life of communities around the world become a concern for all citizens. It follows that bioethical discourse is now supra territorial, transcending its origins in western thinking and including for example indigenous knowledge. It aims to deal with problems such as pandemics, malnutrition, hunger, and climate change, where new coordinated global policies and actions are our best chances in managing catastrophic effects. It looks at the relation between global markets and problems such as organ trade, medical tourism, corruption, and bioterrorism. Furthermore, it looks for answers as older bioethics issues are redefined in different contexts: for example, the concept of informed consent is challenged in clinical trials in countries with economies in transition and developing economies where cultural traditions clash with individual decision-making. In a globalized world, the ways we deal with such problems often have consequences in other countries. As nations are joined in markets, their transactions and interconnections can either have a positive or a negative effects on the impacts of these phenomena on society and culture,
especially between countries with developed economies on the one hand and countries with economies in transition and developing economies on the other hand. International cooperation and action in support of national efforts are required, and even if moral values differ, finding a common ground is warranted by our common participation in the world community. The establishment of the normative framework of the Declarations constitutes bioethics as a ‘global moral community’ with shared responsibilities and values (Ten Have and Gordijn, 2014).

Bioethics balances the tension between personal liberation and affirmation of autonomy, with the need to extend equality to groups traditionally discriminated against. The UDBHR clearly establishes this social focus of bioethics: it refers to the fundamental principles of equality, justice, equity, non-discrimination, solidarity and cooperation, along with social responsibility and health.

Science and technology – while often controlled by particular private and governmental powers – are society’s resources in the fight to eradicate poverty and promote peace, health and the protection of the environment. It follows that scientific progress should not be exploited as an instrument for reinforcing inequality. If the ethical perspective is not taken into account together with the epistemology and methodology, the risk of abusing human rights and contributing to inequalities is great. While the idea of sharing the benefits of research has yielded results against the reproduction of power relations, it has also attracted criticism in terms of a top down charitable character. The democratization of the production of knowledge is therefore a goal that is more attuned to the pluralistic and inclusive values of modern bioethics. The opening up of the agenda to active participation of countries with economies in transition and developing economies, and the support of infrastructure projects in education, research and clinical practice is the basis of an effective knowledge-sharing policy. According to Article 14 of the UDBHR, access to quality health care is fundamental, together with access to adequate nutrition and water, the improvement of living conditions and the environment, the elimination of marginalization and exclusion of people on any basis, and the reduction of poverty and illiteracy.

A socially responsible perspective in which the factor of global justice thus becomes central calls for a focus that has less to do with sophisticated technologies (the frontier bioethics) than with the fight against structural injustice, marginalization and exploitation of vulnerable populations (everyday bioethics). Issues that affect a limited and privileged part of the word cannot determine the bioethical discourse of the near future. The bioethical discourse should rather promote the structural changes that will sustain public health. At the same time, frontier issues that might not seem immediately relevant for all countries also need to be reflected upon with the same perspective, in order to avoid worsening the already increasing divides within and between countries. Because the issues of social
justice and equality are contingent on power relations, these have to be balanced by citizen participation. NBCs are constructed as entities that invite power sharing between experts, decision-makers and citizens. They are forums where scientists, policy-makers and lay actors together understand the challenges linked to new developments and scientific applications. In NBCs, ethics are not the proprietary realm of scientists or health care professionals, but rather a multidisciplinary, pluralistic, deliberative project. In frontier issues, social imagination shaped by novels, cinema, literature, and cultural narratives, plays a key role in orienting research and policies.

2. The normative framework for public engagement

Bioethics is a field of knowledge production in which the democratic value of the public common good is consecrated. As it deals with issues that emerge in the fields of life and biological sciences, the particular definition of the public common good here refers to public health and the wellbeing or health in a widely defined way. The public accountability of bioethics necessarily positions it in relationships with the political and economic field. In terms of interactions with the market and the State, bioethics legitimates its function as the space for reflection on ethics by invoking a set of values. These values defend the field’s autonomy and they are enshrined in the Declarations adopted by UNESCO Member States. They refer back to the public as their legitimating entity and they are themselves the product of democratic deliberation. These principles are interpreted and applied in the practices of the NBCs in the UNESCO Guides for NBCs. Every day, the frontiers or borders between bioethics and ethics of science and technology become more blurred because many medical devices, research and interventions, are used and developed out of the health dimension. Nevertheless, they deserve the same ethical considerations.

The UDBHR defines the universally acceptable norms, principles, and procedures in the field of bioethics. While not a legally binding document, it draws on international human rights law and in particular from the Declaration of Human Rights (1948). ‘It is thus conceived as a group of general provisions and principles that allow for a better evaluation of the implication of ethical issues at stake and to provide assistance in decision-making in this field’ (Ten Have and Gordijn, 2014).

In the UDBHR, institutional bioethics is advised to instigate informed pluralistic debate with the widest possible involvement of the public. This is based on the acceptance of the increased dialogue on bioethical issues in the public sphere. Debating these subjects in public opens up the possibilities for citizens’ active involvement by the identification of relevant stakeholders and communities (e.g. teachers, lecturers, consumer association advocates, etc.) It is understood that the sensitization and engagement of the public
favour awareness, thereby empowering citizens to exercise ‘their autonomy and individual responsibility’ (Article 5). While the public is increasingly aware of the difficult ethical choices, these are often complex issues, as exemplified in genetic research. The public should then have access to current and quality information in order to participate effectively. In addition, all persons and bodies concerned are to be included, and the varied socio-cultural religious, philosophical, and other relevant opinions are to be taken into account. It is important to note here that ‘the public’ is not homogenous and that NBCs should identify who they wish and need to interact with, including deliberate efforts to target marginalised groups as per the issue at hand.

Public debate is explicitly mentioned in Article 18.3 of the UDBHR: ‘Opportunities for informed pluralistic public debate, seeking the expression of all relevant opinions, should be promoted’. In Article 18.1, the principle of the ‘appropriate sharing of knowledge’ is introduced where knowledge is qualitatively described: ‘best available scientific knowledge and methodology’. Furthermore, Article 19 (d) states that Ethics Committees should ‘foster debate, education and public awareness of, and engagement in, bioethics’. Public debate and awareness raising are therefore instrumental in ensuring that an ethical framework of respect for human rights underpins the intersection of science and policy.

With regard to the work of NBCs on the field, the necessity of public engagement is articulated in a number of passages in the UNESCO Guides for NBCs (see Guides 1 and 2).

Guide 1 delineates it as significant part of their purposes:

‘To publish recommendations on bioethical issues and thereby influence policy-making and increase public awareness and participation. When government advisers need to respond to advances in the basic and behavioural sciences as well as biotechnology, such recommendations may eventually serve to influence the formation of new legislation and contribute to public awareness and debate’.

‘To provide a forum for discussions at the national level of a plethora of bioethical problems, issues and particular cases that have received public attention through extensive media coverage, e.g. press conferences, publications, television and the Internet’.

Furthermore, engaging the public is a key aspect of their functions:

‘The committee should offer a platform to deliberate the appropriate uses of biological and biomedical technologies’.
A further task is to facilitate a greater understanding of bioethical problems and dilemmas not only by members of the various health professions and the scientific community, but also by media professionals and the lay public.

The public is also a factor that can come to play in the committee’s self-evaluation process:

‘External evaluation may also be of an informal nature. The media may discuss a committee’s operations or a public official may focus on it at a public hearing or during an interview. These evaluations may sometimes produce significant effects, perhaps by generating a public demand for a change in policy or personnel’.

The public as a legitimating entity for the NBCs is clearly identified in this passage:

‘Credibility is not granted or bestowed; it is earned. It is earned when the Committee persuades its constituency that the Committee’s work is defensible, legally and rationally, and that it is rooted in traditions that have gained general acceptance. Committees must constantly tend to their credibility; which is to say that they must always put at the front of their minds the need to ensure that their work earns the respect of their constituencies’.

The role of NBCs in dealing with power differentials is related to their public accountability:

‘Unless informed by the media or marketers however, the public remains unaware of the results of clinical trials and thus dependent upon others to safeguard their interests. These others – academics, government agencies, scientists, clinicians and journalists – can only perform this function if they are granted access to pertinent information. But sponsors, seeking to maximize sales, protect proprietary secrets and minimize competition, may have powerful incentives to keep some of this information to themselves. This has led to the appearance of gag clauses in research agreements between industry sponsors and scientific and clinical researchers.

The role of media in conveying and influencing public opinion is also addressed:

‘The role of the media is apt to be decisive. For apart from narrow sections of the biomedical community, the public may be entirely unaware of the Committees’ work, probably even of the Committees’ existence. It is the media, usually highlighting spectacular successes and failures, who bring the Committees to public attention’.

In Guide 2, more practical advices are offered in terms of media relationships:

‘Bioethics Committees, especially those established at the national level of government and within health professional organizations, can often benefit from media exposure,
provided they have adopted procedures and policies in full cooperation with their secretariats’.

‘Press briefings, seminars, conferences and informal meetings may also aid in creating an atmosphere of friendship and understanding. Care should be taken to educate reporters so their articles do not mislead the public. Though not expert in bioethics or health care, reporters are trained to grasp a few central themes and reshape them for mass consumption. They should not be addressed with jargon nor patronized as ignorant, but rather approached as skilled professionals in their own right, who perform the vital function of communicating the Committees’ work to the public. Good relations with the media can pay high dividends’.

The media contribute to the formation of public opinion. NBCs should keep in mind that 1) the media are not a neutral forums, but have their own imperatives of narrative, their own audience appeal factors and may also be politically influenced by others, and 2) the media exist in a triangular dynamic with the public and policy-makers. Lastly, media impact is often more on policy-makers than on the public, with the former being more responsive to media publicity and persuasion than the latter. NBCs therefore need a clear understanding of the media in their country, what role they play, where and how they can best articulate with them.

It is evident from the Declarations and the Guides that NBCs relationship with the public is constructed in two ways: a) they are themselves participatory entities. Their membership includes experts from a multiple of disciplines, together with social and lay actors; B) they are advised to act as public forums, instigate and host the dialogue on ethics. Both of these aspects of their public character rely on dialogical relationships because reflection on bioethical issues are performed in deliberation. The goal of the deliberation process is to serve the public and to influence policy; thus, it is performed in the public sphere. This is precisely the realm where committees look to make substantial contributions to citizens’ rational deliberations. The combination of a critical perspective on public health together with the deliberative character of the committees, warrant a theoretical grounding of NBCs’ practice on deliberative democracy theory, which is discussed in Part 2.
1. Bridging the Gap between Experts and Citizens

In the UDBHR, the public dialogue that bioethics should inform and instigate is framed as ‘public debate’. It is important to note that the terminology that refers to public involvement activities is varied and includes terms such as debate, participation, engagement, dialogue, education, consultation, etc. For the purposes of this Guide, these different terms will be used interchangeably, although these are not value free, but are rather associated with the theoretical paradigms they originate from, which range from the conflictual to the consensual theories of democracy. The very term ‘debate’ that the UDBHR makes use of, reflects the conditions of public dialogue when it comes to bioethical issues. These often emerge as controversies that lay the ground for moral disagreement.

Controversies occur as traditions encounter other traditions that might threaten or destroy one another, and new orders are introduced. Technological innovation plays a crucial role in these processes. In modern societies, technological innovation is valorised, as it promises new possibilities for the improvement of our lives. Nevertheless, these are often contested developments that are not equally enthusiastically received. The controversies that arise are rooted in an intermingling of anxieties: worries about the physical effects of the technologies and about their socioeconomic effects, and ambivalence regarding their moral character and the real uncertainties of the achievements of converging advances and results.

The management and resolution of these anxieties is a constant effort of democratic polities. Indeed, they are rooted in a fundamental tension that exists in modern societies. On the one hand, we are increasingly depending on expert systems, scientific knowledge and its applications. Expert knowledge is exclusionary, as it is produced within fields that grant access to entry on the basis of formal qualifications. On the other hand, our normative democratic frameworks call for collective decisions that include all citizens and diverse types of knowledge. The tension between experts and lay actors is pervasive in late modernity and it touches upon the functions of NBCs. Public engagement is discussed in this Guide as a way to manage this primary tension between competence and legitimacy.
Disagreement on new developments that can reach the level of controversy in the public arena is linked with two types of deficits (Bauer, 2002). The first is a deficit in information and can be distributed to all involved actors: among a non-expert public, it can include ignorance about widespread ideas, opinions and attitudes. Among innovators and policy-makers, the deficit can include a poor understanding of the public and mistaken understandings of public opinion. It is also important for NBCs to take into account the deliberate (disinformation) as well as the unintentional (misinformation) promotion of wrong information.

The second type of deficit relates to democratic legitimation. The decision-makers, whether innovators, coming from regulatory and policy-making bodies, or mediators of debates, require legitimacy for their public actions. Legitimacy reinforces trust, and trust in expert systems and their institutions is essential for the continuity of the social order. The public and the stakeholders can procure this legitimacy by procedure. Public engagement is then the practice that includes these procedures towards democratic legitimation.

Exclusionary perspectives on public policy contest the value of ‘lay’ contribution and other kind of knowledge, including indigenous. In most countries, the debate over contented issues is polarized: actors take position for or against according to which they process information (Bauer and Gaskell, 2002). The sceptical public is mostly considered ‘lay’, whereas the advocates of techno-scientific progress mostly exhibit scientific credentials and specialized knowledge. This is where the two tensions, scepticism and optimism, and expert versus lay actors overlap in terms of another modern antinomy, that of danger and opportunity. Lay actors perceive risk, which can incite a sense of danger, or a way out to opportunity, differently than experts. This difference has been explained in the past with the use of the ‘cognitive deficit’ model. This was based on the assumption that expert knowledge provides rational benchmarks for the assessment and prevention of risk. The objective risk identified by experts has been found to diverge from the perceptions of risks by lay actors. Nevertheless, modern research recognizes that scientific work is equally subject to values and normative assumptions, an approach that signifies a break from the positivist understanding of science. Even more, the quantitative methods of measuring risk that are employed by experts are contrasted with the richer, qualitative understandings of risk expressed by lay actors. As a result, lay knowledge is no longer treated as an erroneous deviation from a scientific standard, nor as an epistemologically vacuous. It is appreciated as an autonomously validated source of knowledge that often contains valuable insights and experiences.

The inclusion of the reflexive knowledge of citizens in the public dialogue therefore sustains social integration through the reinforcement of trust. In this sense, participation, the inclusion of marginalised social groups, and deliberation, the inclusion of overlooked
Perspectives and arguments, coincide. Rationality and legitimacy in situations of disagreement can be mutually strengthened by deliberative procedures. Arguments in favour of deliberation and participation are then both normative and functional (Hansen, 2010). Normative approaches see them as the embodiment of democratic ideals: they empower citizens and are subject to evaluation according to their ability to democratize policy-making. Functional approaches focus on their potential to maintain trust, prevent future controversy and lead to the acceptance of change that is sensitive to social and ecological considerations.

In addition, 'Normative ethical reasoning obviously does not float in a social vacuum. It is performed by concrete persons with their own moral convictions and situated in socio-cultural contexts, which often involve specific social roles and moral rules. Even if ethical reasoning aims at an “ultimate justification” or a radical critique of particular norms, it usually has to start from some set of consensual moral convictions on what is important, right, just.’ (Schicktanz, Schweda and Wynne, 2012). In applied ethics, this is captured in the ‘reflective equilibrium’ between theoretical reasoning, ethical principles and concrete moral judgements, described by Norman Daniels (2003).

Furthermore, public inclusion is a mean to manage complexity. This implies a view on modern societies, as complex mechanisms that traditional top down approaches of governance can no longer manage effectively. The technical and social complexity is delegated away from central bodies to self-governing networks, a transition that challenges traditional conceptions of democratic accountability. Legitimation is then linked to the transparency of policy processes and the integration of the varied range of stakeholders. Public engagement, by means of inclusion and participation, embodies the ideals of deliberative democracy. As we will see in the following section, central to this approach is the idea that collective decisions can be reached only after that a collective examination of arguments and perspectives have been considered. In other words, all who are affected by the decisions should have the chance to voice their views and all relevant viewpoints should be heard.

Last but not least, the UNESCO Priority Gender Equality Action Plan for 2014-2021 (GEAP II) provides an operational framework for the implementation of Priority Gender Equality. It explains what gender equality means for UNESCO, and it should be taken into account by NBCs in their engagement of the public, so that gender equality is advanced. It is everyone’s responsibility to promote women’s empowerment and gender equality through gender mainstreaming.
2. **Deliberative Democracy**

The idea that democracy is not about the transformation of preferences through their mere aggregation but rather through deliberation, is central to one of the major democratic theories. Deliberative democracy is any one of a family of views according to which the public deliberation of free and equal citizens is the core of legitimate political decision-making and self-government (Bohman, 1998). Let us acknowledge here that the real power differentials (e.g. gender and class) constitute a blind spot of this insight, together with the belief that rationality can drive decision-making. However, emotional factors play a powerful role. This ideal is mostly associated with the work of Jürgen Habermas, who suggests that cognitive, normative and expressive disagreements can be settled, in principle, through argumentation among free and equal discussants. Deliberative democracy can then be understood a) as a process of collective decision-making with the participation of all those affected by the decision or their representatives, and b) a means of reasoned argument offered by and to participants who are committed to values of rationality and impartiality. It is organized around an ideal of political justification requiring free, public reasoning and equal citizens. Arguments against or for the decisions have to be explained to the affected people in terms that they are capable of accepting (Besson and Martí, 2006). Hence, in the core family features of deliberative resides a notion of expanded public involvement that is not restricted to political representatives, media, technocratic bodies and other elites. Deliberative models see communication on policy as mutually shaped by and shaping the preferences of the actors that participate in the processes. These changes occur through persuasion, rather than manipulation, coercion or deception (Moore, 2010).

Let us have a look in more detail at the ways that deliberative procedures support the democratic political process taking our cue from the analysis of Gutmann and Thompson (2009), who identify four characteristics in deliberative democracy.

The fundamental function of deliberative democracy affirms the need for justified decision-making. Citizens and their representatives are expected to justify the laws they would impose on one another. In a democracy, this is a two-way responsibility: leaders give reasons for their decisions, and respond to the reasons that citizens give in return. Nevertheless, deliberative democracy includes other forms of decision-making besides deliberation, as long as the use of these is justified in a deliberative process. Its first and most important characteristic, then, is its reason-giving requirement.

These reasons appeal to principles that actors willing to cooperate cannot reject. They are neither merely procedural, invoking a majority, nor purely substantive. They are reasons that should be accepted by free and equal persons seeking fair terms of cooperation. This idea
resides on the moral value that persons are not passive subjects but rather autonomous agents who take part in the governance of their own society, directly or through their representatives. The reasons that leaders and citizens give each other produce justifiable decisions and express mutual respect. Assertions of power and expressions of will, albeit constitutive of democratic politics, cannot prevail without reasonable justification.

The second characteristic of deliberative democracy is that the reasons given in this process should be accessible to all the citizens to whom they are addressed. This relates reciprocity with the idea of publicness. Deliberation should take place in public and address the public. A deliberative justification that fails to be understood by the people that it addresses undermines the whole deliberative process.

The third characteristic of deliberative democracy is its provisionality. It aims to produce a decision that is binding for a period of time. In deliberation, the participants argue so that they influence a decision or a process that will affect how decisions are made in the future. At some point, the deliberation temporarily ceases, and the leaders make a decision.

This continuation of debate makes the process of deliberative democracy dynamic, which is its fourth characteristic. While the aim of deliberation is a justifiable decision, this is not always the case. Furthermore, there is the possibility that the justification will not suffice indefinitely. This acceptance of contingency opens the possibility of a continuing dialogue, through which citizens can collectively reflect on past decisions, criticize and revise them.

One important implication of this dynamic feature of deliberative democracy is that the continuing debate requires the principle of the economy of moral disagreement. During the processes of reason giving, citizens and their representatives seek to minimize the differences with their opponents. This implies an acceptance of disagreement. The practice of the economy of moral disagreement promotes mutual respect, which is the basis of deliberative democracy. By economizing on their disagreements, participants can continue to work together to find common ground, if not on the matter at hand, then on policies that seem more fertile for finding agreement.

Bringing the four characteristics together we can define deliberative democracy as a form of governance, in which free and equal citizens (and their representatives), justify decisions in a process in which they give one another reasons that are mutually acceptable and generally accessible, with the aim of reaching conclusions that are binding in the present on all citizens, but open to challenge in the future.
3. The public sphere

The deliberative approach departs from the aggregative models of democracy in adding nuance in the political procedures. It rests on the ideas of rational persuasion and the identification of the factors of conflict disentangling interest, expediency and values. It has been argued that this rationale has been present in bioethics since its inception (Moore, 2010). Bioethics forums, an aspirational function of NBCs, encourage argumentation and reasoning in an open and fair manner thus strengthening the relationship between rationality and legitimacy. The deliberative dimension that NBCs seek to add to the political has been defended by relevant research in the field. Albert Dzur and Daniel Levin (2007) argue:

‘As a public forum, a commission’s ability to address public concerns, and not just professional or scholarly debates; its ability to engage public ways of moral decision making; and its capacity to inform and encourage public reflection are all critical indicators of its success at fulfilling democratic purposes. These measures are informed by democratic theory, but they are also immanent: they are based on our understanding of the role of bioethics as a reform discourse bringing external values important to society into the medical domain, based on our interpretation of the public forum role of advisory committees, and based on our analysis of how bioethicists themselves have assessed the ethical deliberation of bioethics commissions’.

This thinking is associated in particular with the writings of Habermas on communicative rationality and the public sphere. The latter concept is central to the theories that form the family (and academic field) of deliberative democracy. Habermas (2001) defines the public sphere as ‘a realm of our social life in which something approaching public opinion can be formed. Access is guaranteed to all citizens. A portion of the public sphere comes into being in every conversation in which private individuals assemble to form a public body. They then behave neither like business or professional people transacting private affairs, nor like members of a constitutional order subject to the legal constraints of a State bureaucracy. Citizens behave as a public body when they confer in an unrestricted fashion—that is, with the guarantee of freedom of assembly and association and the freedom to express and publish their opinions—about matters of general interest’. Public sphere in modern societies requires means of communication for the transmission of information and influence and this is the function of the media. Public opinion is also formed in the public sphere, and the term refers to the tasks of criticism and control that a public body informally, and when voting, formally, practices vis-à-vis the ruling structure organized in the form of a State.
For Habermas, the public sphere links the private life world of citizens with the systems of society. We can mention here that in today’s world, the private often becomes public and the public is too often private. It requires that citizens leave their privacy and appear in public to debate matters of common interest. The purpose is for public opinion to be formed, which will influence decisions and policies. This abstraction maps on the procedures of bioethics forums, especially as they offer opportunities for deliberation on moral disagreements.

The ideal of the public sphere is reached when three requirements of communication are met: a) equality and reciprocity, b) openness and adequate capacity, and c) a discursive structure. Equality and reciprocity refer to the value that calls for all actors to have equal possibilities for participation, and that they reflect and respond in argumentation. Openness and adequate capacity refer to the principle that all arguments and viewpoints are considered including those neglected due to power differentials. The requirement for a discursive structure means that public deliberation must be based on reasoned argumentation; it cannot be hinged on status, power, wealth, intimidation or coercion (Hansen, 2010). All citizens constitute the public sphere; after all, when it comes to dealing with expert systems we are all potentially considered ‘lay actors’. Equal opportunity of participation is then supported when deliberation in the public sphere is accessible and comprehensible to ordinary citizens. To this end, experts are required to communicate their knowledge in a language that it is accessible by all participants.

The concept of public sphere has been itself a subject of debate in the academia. Questions regarding its normative character vis-à-vis the pragmatic conditions of communication, the relation between publics and the public sphere and indeed its fragmentation in multiple spheres have occupied the researchers’ attentions. While this discussion is beyond the scope of this Guide, it would be useful to look at some of the arguments with a view to map this theoretical concept on the NBCs.

Habermas talks about three types of public spheres and their associated publics: episodic public spheres, public spheres of organized presence and abstract public spheres. Episodic public spheres are formed in the casual conversation of the everyday in the streets, the cafes or restaurants, while organized public spheres can form when people attend public events such as theatre plays, concerts etc. The abstract public field is constituted through mediated communication and it brings together listeners and viewers that are not physically co-present. This signifies the acceptance of the globalized communication systems as equally formative of the public sphere, as much as the face-to-face situations. Looking into episodic public spheres where people vent their frustration with power structures, government, policies, authorities and debate on moral issues has significant discovery value of the discourses that circulate in society and the matters that need public
discussion and attention. In spheres of organized presence, dialogue occurs in a more disciplined and formalized way: there is an agenda of issues to be discussed according to procedural rules. Civil society, NGOs and voluntary organizations are part of the latter spheres and they share these characteristics with NBCs. Abstract publics come together through the media through processes of time and space distanciation. They mediate the discussions that occur in other fields and thus have the power to influence them. While Habermas takes stock of these differentiations, he sees how the discursive nature of these public spheres, the fact that they are linked by the use of ordinary language, makes them porous. He then sees the public sphere as a unified discursive entity, ‘a text continually extrapolated and extending radially in all directions, is divided by internal boundaries into arbitrarily small texts for which everything else is context; yet one can always build hermeneutical bridges from one text to the next’ (1996).

Within deliberative democracy, there is a division between those who focus on deliberation in institutional contexts and those who consider the public sphere as the ideal communicative situation. This has been framed along an antinomy between ‘liberal constitutionalism’ that refers to the former accounts and ‘discursive deliberative democracy’ that refers to the latter. The academic field is alternately divided into micro and macro models of deliberative spaces. Micro deliberative theorists focus on the ideal conditions for deliberation. Macro theorists consider deliberative democracy in the unstructured and open discursive forms of deliberation in the public sphere, which is outside the sphere of the State, as Habermas argues.

The conceptualization of deliberative processes in terms of an integrated system of discursive spheres has been argued to overcome this divide. According to this approach, spheres can be either micro, macro or mixed. The mixed spheres play a role in bridging the gaps between the other two. They can include experts, policy-makers together with civil society actors and ordinary citizens. Mixed designs are then more inclusive and diverse. The participants are exposed to a variety of discourses that refer to the issue at hand that gives them a more informed perspective. Looking at NBCs and their emphasis on communication as public forum, the micro and macro theories cannot map with precision their function. It is therefore suggested that they are in fact mixed discursive spheres (Moore, 2010).

Matters that preoccupy the macro theorists will rarely be of critical importance in the pragmatic conditions of NBCs. Whether NBCs form public spheres of their own, or they are part of a unified public sphere are of a lesser priority when compared to the difficult tasks of realizing the principles that deliberative democracy calls for. Indeed, the focus on principles and values is a determining feature of the deliberative approaches. While this has attracted criticism from theorists with a more conflictual understanding of the social,
deliberative democracy’s strong normativity is an advantage for the purposes of NBCs. When it comes to serving the public, Bioethics Commissions assume an educational role that is two-fold. On the one hand, they make the effort to educate the public on bioethical matters so that citizens can deliberate on shared knowledge. On the other, they educate participants in the ways deliberation is practiced in a democracy. As Dryzek argues, in the cases of divided countries deliberative models have better chances compared to the agonistic ones (2005). The fundamentals of rationality and mutual respect, experienced by the members of a bioethics forum as democracy in practice, has a strong educational value. The experts and lay actors that come together to deliberate train each other in democratic deliberation, and they carry this experience back to their social groups and communities.

4. Understanding Consensus

The idea of consensus, the eventual coming to a decision with regard to the contested issues at hand, is important in deliberative procedures. Consensus is commonly related with the idea of an ethical unity in the social, a kind of pre-existing agreement that is to emerge and be articulated during deliberation. This assumption is also shared in some of the literature on deliberative democracy and bioethics. Nevertheless, this too is a matter where theoretical approaches diverge. After Gutmann and Thompson (2009), we identify two schools of thought in terms of their answers to the question: should deliberation aims for consensus as the manifestation of common moral ideal or through setting out the best ways for people to live in a pluralist society?

The republican tradition of deliberative democracy aims for a consensus of the former type, one that realizes a solid social unification. While realizing that this is an ideal situation they nevertheless consider it an aspirational goal worth pursuing. On the other side, the more liberal deliberative democrats hold that it is more important that people cooperate while recognizing differences and accepting contrasting points of view. According to this strand of thinking, disagreement is fundamental to the human condition. Both sides then concur that there is the possibility of a minimum agreement when it comes to deliberation on the rules that citizens and representatives debate. This can be found in that fair terms of cooperation between free and equal persons.

For consensus democrats, this is not enough for the good of society. They claim that a comprehensive common good should be the goal of deliberative procedures, albeit acknowledging that this can be an elusive ideal. The difficulties of achieving it are to be found in the incomplete capacities of the citizens or the lacking practices of the polity; both can be remedied. At the root of this thinking is the dismissal of the idea that political
disagreement is ingrained in the social and cannot be (or should be) eliminated. In contrast with pluralist democrats, they are not willing to accept that agreement on terms signifies a deep, substantial consensus; they argue that it produces passive citizens who can be easily swayed by consumerism and abandon their aspirations to be producers of public goods.

Pluralists are concerned with the effects of power on democracy, and they see its effects in the pursuit of a universal common good. Since moral differences are pervasive, the democratic solution is not their eradication, but rather the tolerance of difference and diversity. While they still consider deliberation as the means by which societies reach basic agreement, they are sceptical towards the complete elimination of opposing voices. Moreover, it is important to acknowledge the differences, the reasons for those differences being to better understand the challenges to gain the consensus or why it is impossible to reach it.

In the field of bioethics, the republican assumption of a common ethical unity has also been challenged. With regard to the role of bioethics in mediating the social debates, Dodds and Thomson (2006) have argued for the model of ‘contested deliberation’, according to which moral consensus is not the ultimate goal of deliberative procedures. Instead, they propose that the work of NBCs should be preparatory to open participation. This function is intended to open up public debate by providing or inviting well informed, articulate expressions of the diversity of moral points of view. For the bioethics commissions that focus on their public forum function, their primary work is then not the dissemination of scientific knowledge, but rather the preparation of citizens to enter the public debate.

If consensus is not the demand of the deliberative process, then it is the voicing of the conflicting arguments that legitimates them in terms of their democratic role. Thus, NBCs are best understood as public forums that do not presume a pre-existing ethical unity to be realized in their deliberative proceedings. They are rather welcoming to the emergence of a pre-existing ethical pluralism when expert, policymakers and citizens convene; in this sense, they facilitate a ‘discursive modus vivendi’ (Moore, 2010).

5. Deliberation on Bioethics

Deliberative democracy’s focus on disagreement and public decision-making render this political theory relevant in understanding the conditions of moral debate in bioethics. NBCs function as forums of public deliberation on matters where moral disagreement emerges. They are not, as the constitutionalist perspective would dictate, an opaque sphere where moral disagreement is enclosed to be acted out between expert debates, away from social pressures. As society reflects on its fundamental values, the bioethical issues become intertwined with the political process. Deliberative democracy encourages the discussion of fundamental values in all phases of the democratic process.
Citizens, experts and policy-makers participate in deliberative processes within bioethics forums so that their disagreement can contribute to the polity. We will follow Gutmann and Thompson (1997) in identifying the purposes of deliberative procedures in bioethics. Their first purpose is that of legitimating collective decisions. Here, the issue of moral disagreement relates to the scarcity of resources. In the context of public health this could refer to matters of health care distribution, organ transplants etc. which are limited. Deliberation can legitimize the decisions over who gets access and who does not in matters that are highly contentious and sensitive. This calls for the expansion of the deliberative forums to include more of the voices that are typically left out. While this inclusionary vision risks the intensification of moral conflict, it breaks down the power relations that would prevent legitimate dissatisfaction to be heard. Reaching consensus is not ideal per se in these situations. The aspiration is for a deliberation that is justified by both sides on the basis of terms that all accept.

The second purpose of deliberation is to encourage public-spirited perspectives on public issues. This deals with another source of moral disagreement, that of limited generosity. Deliberation here has educational purposes: by putting people in positions that direct their reflexivity outwards towards their social environment, it looks for social cohesion. It is understood that self-centred individualism will not be eradicated, merely on the basis of dialogical relationships. Nevertheless, public-spiritedness can be supported by a number of conditions. These include the level of competence (how well informed deliberators are), the distribution of resources (how equally situated they are), and the open-mindedness of deliberators (the range of arguments they are likely to take seriously). This is where the individual attributes of the participants come to matter. The diversity of voices and arguments is not the most critical point of a deliberation; it is rather the dispositions of the members of the procedures. They should come to deliberate with a will to consider their opponents’ perspectives, open to changing their minds as much as persuading. Hence, the deliberative process can be productive when it is not incorporating power relations and the particular interests of the representatives. The participants then are advised to not think of themselves as negotiators for their guilds of collectivities, so that the process is not reduced to interest group bargaining.

The third purpose of deliberation, to promote mutually respectful decision-making, responds to the problem of incompatible moral values. Even if we assume that all previous requirements are met, and participants are open to difference with altruistic motives, there are thorny moral issues that societies historically struggle with. In bioethics matters such as euthanasia, abortion, and children’s informed consent are typically divisive. In such cases, the aim of deliberation is to promote the value of understanding the merits of the opponents’ argumentation. It is to the interest of the forums to sort out the self-interested arguments that often form around these fundamental disagreements.
This ensures that participants economize on their disagreements: they understand the issues where irreconcilable differences exist, and identify the areas where there can be deliberation, negotiation or compromise. This practice strengthens mutual respect as parties may continue to disagree on the morally important issues before they reach collective decisions. For bioethics commissions it may be more effective to direct focus on issues where some consensus can be achieved, rather than those that invite strong polarizations. If these cannot be avoided, deliberation should focus on mutual understanding. The correct identification of the deeper moral conflicts is equally important to reaching a conclusion.

The fourth purpose of deliberation is to help correct the mistakes that citizens, professionals, and officials make when they take collective actions. This is a response to the last source of disagreement, the incomplete understanding that underpins most moral conflicts. A well-constituted bioethics forum advances both individual and collective understanding. Through these dialogical relationships, participants come to address their assumptions, adapt to criticism and develop views and policies that can be better defended in public. Bargaining and negotiation, which often occur in deliberations, activate the reflexivity that is not guided strictly by self-interest, but is informed by the sense of responsibility to the general public. It follows that the outcome of deliberations is provisional. While decisions are eventually made these can be subject to revision in the future. This is an understanding of the fluidity of the social and the lack of closure that is associated especially with matters of ethics. Deliberation continues in stages, as proposals are discussed and revised, in what is known as the reiteration of deliberation.

In conclusion, deliberative democracy in bioethics ensures that there exists an active two-ways process between the public and the institutions responsible for its health. It is a democratically informed way to engage the public in discussion and partner with them in decision-making and policy-making processes. In this way, the stakeholders are joined in the creation of knowledge and the results of its application. In terms of its value for public health, deliberation is expected to improve understanding of the moral issues associated with policy choices, contribute to public accountability, increase capacity-building, and promote a social solidarity that is based on trust and tolerance.
PART III

PUBLIC ENGAGEMENT TOOLBOX

1. DELIBERATIVE APPROACH: ENHANCING THE NATIONAL BIOETHICS COMMITTEES’ (NBC) FUNCTIONS

The Guides for the NBCs are of course not mandatory and prescriptive documents. While they aim to offer knowledge and advice to committees in accordance with the principles of the Declarations, they allow for a diversity of theoretical and practical approaches when it comes to groundwork. This diversity is grounded on the pragmatic level: committees differ in their establishing bodies and mandates and, as such, this affects their roles within their nation-states. It follows that the degree of public engagement and the forms of public participation they can accommodate is necessarily contingent on their status.

While acknowledging different types of committees, the UNESCO Guides on establishing committees (Guide 1) and setting out their procedures and policies (Guide 2) explicitly situate them in the public space. In particular, Guide 2 states: ‘The decision to establish new Committees is driven by a number of factors, not least of which is the need – now recognized by scientists, health professionals, and many others – to share in deliberating complex bioethical issues not only with colleagues (life scientists and various health specialists) but also with other stakeholders, including the media and the public. Here, it is important to recognize what has occurred in the field of bioethics since the late 1960s: bioethical issues, including complex cases and dilemmas, are no longer left for bioethicists alone to analyse’ (UNESCO, 2005b).

The deliberative character of the committees as means to address controversies is also spelled out in Guide 2: ‘these Committees serve as platforms for deliberation not only on general bioethical issues, but also on particular dilemmas raised as a consequence of advances in the biological/biomedical and behavioural sciences and biotechnology. They tend to focus on bioethical issues that have recently emerged or are soon expected to receive the attention of the media and the public’ (UNESCO, 2005b).

The nature of this publicness is further defined to include an educational dimension alongside the role of instigator and facilitator of public dialogue: ‘The committee members in addition may be charged with educating the public and stimulating widespread discussion of bioethical issues. Thus, they may contribute to placing an issue on the
social or political agenda or defining the problem or validating a vocabulary or mode of discourse’ (UNESCO, 2005c).

Hence, NBCs assume multiple roles that, while clearly demarcated, invite tensions that typically emerge at the intersection of science and policy. On the one hand, they are meant to engage with policy-makers in formal and informal capacities that mostly include advising and consulting. On the other, they are accountable to the democratic public that they educate and with whom they facilitate debates. At the same time, they are determined by tensions between expert knowledge and public legitimation. These antinomies in public bioethics have given ground for debate over the multiple roles of committees in the past (see Kelly, 2003; Dzur, 2004; Johnson, 2006). This has also been captured in Guide 2: ‘How the Committee deliberates must also be decided. In the nature of things, many of its discussions will occur informally and hidden from view. Should it eventually be required to hold open meetings, to publish its decisions or to provide written justifications for these decisions? The Committee’s business is the public’s business, and the public (or its representatives, officials, or the media) may demand openness as a means to accountability. Decision-making, however, calls for candour, bargaining and compromise – qualities that tend to fade with publicity’ (UNESCO, 2005b).

The deliberative turn in the field of bioethics, as documented in the academic and institutional literature, came from the need to address these issues. The empirical and theoretical knowledge that has been produced in the past years in the field of bioethics has stemmed to a great extent from the experience of NBCs. Deliberative democracy has therefore emerged as an autochthonous normative choice. In consistence with the understanding of science as reflexive, it makes sense that this knowledge is reinvested in the practice of NBCs. The conceptualization of NBCs with the help of deliberative democracy provides a stable yet flexible framework that unifies and grounds theoretically their procedures. It lends support to their dual functionality: in terms of their influence on public policy, it adds authority by legitimation, as discussed in Guide 4. With regard to their relationships with the public, it adds deliberative tools to their existing communicative toolbox, thus strengthening their influence and democratic function.

Reflexive self-regulation is a fundamental aspect of NBCs. As per Guide 2: ‘Finally, Committees would be well advised to call for a review of their internal policies and guidelines at regular intervals of no longer than five to seven years. These internal working procedures and operating policies may (1) be reaffirmed with no or only minor changes; (2) undergo major revisions; or (3) be replaced or eliminated. A periodic review will ensure that internal policies and guidelines do not outlive their usefulness. In any case, the leadership of an association may require that it formally receive these proposed procedural changes from its Bioethics Committee so it may review them before giving its
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final approval to the chairperson’. With regards to the public it is also up to the committee to choose the most appropriate level of communication, as stated in Guide 2: ‘Determine how the media and the public will be informed of the Committee’s activities: advising, recommending or decision-making’ (UNESCO, 2005b). This section aims to inform NBCs of the options they have according to their answers to this set of questions: do you want to inform, consult, collaborate with or empower the public to make a decision?

2. Who is the public?

Before moving on to the public engagement options that NBCs can employ, it is fitting to disambiguate the idea of the public. We can get a first idea of what it entails from the Guide 2 listing of relevant social groups that can be considered for NBC membership: ‘Typically, basic scientists, clinical researchers, physicians, nurses, pharmacists, bioethicists, clergy, health lawyers, behavioural scientists, social workers, patient advocates, administrators, laypersons and public officials are among the relevant categories represented’ (UNESCO, 2005b). In consistence with the principles of bioethics, this recognizes both the stakeholders and the public’s involvement in NBCs procedures. Nevertheless, these are not understood as discrete social entities that NBCs should engage with in exclusive relationships. Beyond an out-dated mapping of communication as transmission between a sender and a receiver, the public space in which NBCs operate is considered to be the realm where multiple discourses are articulated in constantly shifting dialectic relationships, based on difference and equivalence. On the pragmatic level, this means that it is impossible to address a portion of the population and contain the effects of this influence within this group. Furthermore, the discursive understanding of communication is consistent with the recognition of citizens’ increased power of self-determination. In modern societies, citizens are monitored; they scan all kinds of news for topics that matter to them personally. Therefore, NBCs should be aware that the information they make available publicly would find its way to citizens through the porous constitution of society.

Since the deliberative approach primarily implies a conceptualization of the public space as a sphere, it will be useful to keep in mind Habermas’ comments on its constitution. He identifies a variety of actors with mediating capacities within it, namely journalists, politicians, lobbyists, interest group advocates, experts, moral entrepreneurs, and public intellectuals:

‘There are two types of actors without whom no political public sphere could be put to work: professionals of the media system — especially journalists who edit news, reports, and commentaries — and politicians who occupy the centre of the political system and are both the co-authors and addressees of public opinions. Mediated political communication
is carried on by the elite. We can distinguish five more types among the actors who make their appearance on the virtual stage of an established public sphere: (a) lobbyists who represent special interest groups; (b) advocates who either represent general interest groups or substitute for a lack of representation of marginalized groups that are unable to voice their interests effectively; (c) experts who are credited with professional or scientific knowledge in some specialized area and are invited to give advice; (d) moral entrepreneurs who generate public attention for supposedly neglected issues; and, last but not least, (e) intellectuals who have gained, unlike advocates or moral entrepreneurs, a perceived personal reputation in some field (e.g., as writers or academics) and who engage, unlike experts and lobbyists, spontaneously in public discourse with the declared intention of promoting general interests’ (2006).

NBCs, as we have already seen, engage in relationships with these actors, and internalize several of these groups’ perspectives through their heterogeneous membership. At the same time, in accordance with the deliberative principle that collective decisions are made with the participation of those affected, they can choose to include members of the general public. In other words, since matters of public health are of concern for the whole of society, the public can be considered as a continuum ranging from individuals to stakeholders, and to ‘the general public’. The concept of general public is supported in the wider institutional field of public health. For example, the World Health Organization states that ‘genetic education should target the general public’ (1997).

Hence, it is heterogeneity that is valued in deliberative processes, as it better reflects the diversity of the polity and supports the goals of deliberation. Participants in heterogeneous groups are then able to learn from perspectives they would not be able to access otherwise and this can be a transformative experience that bolsters civic mindedness. NBCs nevertheless should be aware that they have to adjust for two concerns: dominance and polarization. Dominance of a majority group over another can occur when the deliberative procedure is underpinned by wider social power differentials. These can manifest in relationships of deference, ease of argumentation, etc. Polarization occurs when a group moves to the extreme of their position in an attempt to reinforce their arguments. NBCs can intervene in ways that mitigate these problems: they can provide educational material before the deliberation that will correct misconceptions and provide a common basis for dialogue; they can ensure that everyone gets equal chances to participate and that no one dominates the discussion. NBCs as facilitators of deliberation have to make sure that all voices are heard and that minorities articulate their position, even when it is contradictory to the majority.
3. LEVELS OF ENGAGEMENT

NBCs, depending on their mandate, status and issue at hand, need to reflect and clarify at which level it is appropriate to approach the public. It is hence practical to consider these four levels of reaching out to citizens: information, consultation, involvement and collaboration.\(^5\)

At the **level of Information**, NBCs seek to make the public aware of the knowledge they produce. The goal is to raise public awareness of the committee’s work at whichever stage the committee sees fit (e.g. prior or after significant publications). Additional goals can equally be to collect public opinion and generate momentum for a certain policy that the committee puts forward. The strategies used at this level rely on written, verbal, electronic and visual communication. The tools that can be used range from opinion polls and surveys, periods during which the public can comment, public hearings, and media campaigns. The public notification affordances of the internet are fundamental in this level. The committee’s website not only constructs its institutional identity but also is the repository of the material that can be distributed to other public sphere actors and the public. Typically, the timely maintenance and update of the website is the responsibility of the secretariat with the collaboration/supervision of the press officer. In addition to a well-functioning website, the relevant social networking sites can also be utilized, as they are technological affordances that support the promotion and diffusion of web material to sensitized audiences. Depending on the type of material or action, online tools can be selected: microblogging (e.g. Twitter) to make the public aware of the committee’s activities; online notice boards (e.g. Facebook events) to announce public hearings; video and audio sharing (e.g. YouTube) to disseminate multimedia; streaming services (e.g. YouTube, Periscope) to broadcast public events, etc.\(^6\)

At the **Consultation level**, NBCs proceed to a relationship with the public that is closer to the deliberative ideal, yet the mode of engagement is still relatively thin. Committees at this level seek input from people who are affected by the issue at hand. The public provides views and experiences that the committee can take into account during the stages that lead to the publication of a recommendation in its working parties. Nevertheless, the goals of stimulating public debate, educating citizens, clarifying tensions, and overall improving the quality of the committee’s work can be achieved at this level. The strategies here rely on face-to-face dialogues or their online equivalents in public meetings.\(^7\)

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\(^5\) While the semantic boundaries between these terms are already acknowledged to be blurred, they are used here as analytical categories for reasons of reference.

\(^6\) For an application of social media in Bioethics, see: Chevinsky and Henderson, (2014).

\(^7\) For an example, see the webpage: Nuffield Council’s Future Look meetings in the UK (http://nuffieldbioethics.org/future-work/background-papers-resources/archive)
Deliberative procedures can be employed in the following two levels.

At the level of Involvement, the public is recognized as a rightful participant in decision-oriented deliberations, alongside other stakeholders/representatives. The goal here is to involve the public in problem-solving and decision-making, to build the public understanding of the moral tensions involved, based on different perspectives and scientific data. The deliberative process, in face-to-face meetings or online platforms, creates opportunities for expert and public communication, and the recognition of the underlying relations that shape emergent conflicts.

At the level of Collaboration, committees should explicitly state their statutory authority to involve stakeholders and the public in policy development. Because this level involves sharing of decision-making power, the deliberation seeks consensus. Affected groups, experts, delegates and representatives, policy-makers and the lay public are expected to build the capacity for the implementation of policy. This typically signifies stable relationships of cooperation among them, and in NBCs, one instance of this practice could be observed in their plenary meetings.

In the last two levels, where deliberative procedures are at play, a distinction should be drawn between activities that aim for participants to process the shared knowledge and between those that aim for exchanging information. Concluding, we should also repeat that committees adopt a deliberative modus operandi also by economizing on deliberative events. A combination of the methods available in the information and consultation methods, provided that these are founded on prior deliberative procedures, is equally supportive of the inclusive, pluralist role of NBCs. Methods of engagement that are considered more conventional such as opinion polls, questionnaires, hearings, meetings with influential individuals or groups, and open invitations for comments can be used alongside more innovative methods, such as citizens’ juries and internet dialogues.

4. The deliberative process

Irrespectively of the topic at hand, the participants in deliberation are asked to accomplish a specific task. The deliberative tasks can include the development of policy guidance and recommendations, the setting of priorities and allocation of resources, the evaluation of risks and benefits, the legitimation of decision-making authorities, or the reflection on ethical and values dilemmas. While NBCs may find themselves working with more than one of the above tasks (and in combination), they are mostly dealing with the latter: the task of identifying and reflecting on moral disagreements.
The deliberative tasks are performed as part of a number of methods. The deliberative methods refer to the structure of the process. They differ in terms of the number of participants, the length of the sessions and their iteration. NBCs also should consider the participation of experts, the recruitment method, the personal expertise of the facilitators, and the access to educational material. The following are popular deliberative methods, which NBCs can employ after they consider their goals and issues (Newell, 2010):

**Methods**

**Citizens’ juries**: These are comprised of a small, random, representative group of lay participants (12-24) convened to consider a particular question or issue. Over a number of days, the jury is informed about the issue, hears evidence and cross-examines the witnesses/experts. At the end of this procedure, the members of the jury are obliged to discuss the matter among themselves and make a recommendation. The final report of their deliberation has to note the difference in opinions. A variation of this is the planning cell, where participants are purposively selected. The discussions are held in cells of about 25 participants and they are mostly oriented towards decision-making rather than a debate of values. In contrast with the jury, the public defines the issues in this method.

**Consensus conferences**: This involves a randomly selected group of citizens (10-20) that come together to deliberate on complex issues that require scientific or technical information. Consensus conferences are divided in two stages. During the first stage, the lay participants are briefed and engage in meetings and discussions with experts where they are exposed to differing arguments. During the second stage, they prepare a consensual document where the differing views and opinions are noted. These reflections and conclusions are finally presented in a conference to the wider public where they can be discussed with decision-makers.

**Deliberative opinion polls**: These polls can involve even larger numbers of the lay public in comparison with the previous methods. Typically, several hundred participate and this random sample is designed to be demographically representative. The participants debate over the matter in question, with the opportunity to cross-examine the relevant stakeholders and experts. The group is polled on the issue before and after the deliberation process, thus providing insight through the comparison of their answers.

**Focus groups**: they are mostly small groups of 6-12 purposively selected citizens that gather to discuss an issue with the guidance of a facilitator. They are not required to reach conclusions. The interest here is rather the perspectives and attitudes towards the issue.
Experts or stakeholders are not required to participate and the sessions last no more than 2-3 hours.

**Issue Forums**: they involve variously sized groups of citizens (2-100), who are purposively selected. They are given background material on the issue and they deliberate with the guidance of a facilitator. They are then polled at the end of the deliberation and their answers are then made available to the committee.

**Study Circles**: they involve large numbers of purposively selected people (up to 300) in groups of 8 to 12 participants. They convene 3-5 times and for about 2 hours each time, in order to reach a conclusion for their common concern.

**Town Hall Meetings**: these include by far the largest numbers of purposively selected participants (up to 5000). They are divided into small groups who make use of educational material before engaging in deliberation. Experts and policy-makers are present and they too participate in the discussions. Typically, and according to the iteration of this method with the name 21st Century Town meeting, the results of each table’s conversations are entered into a computer and then processed and reported to the organizers.

**Standing citizens’ panels**: these convene a few times over a year and they can include about 12 people who are purposively selected and can be replaced should the need arise. They are consulted periodically with the intent to ascertain changes in views and attitudes over time.

**Recruitment**

Random selection is commonly used in public deliberation. Citizens are chosen according to social and demographic characteristics, such as gender, age, class, or constituency. This is so that they can be considered representative of a social category in the attempt to reflect the stratification of the wider society. Nevertheless, there are certain limitations to this method. We will briefly comment on the issues that arise with random sampling and look at the alternative recruiting strategies as they emerge from the literature.⁸

NBCs should be aware that random selection often fails to reach marginalized groups. Even if financial incentives are used, individuals from lower income and class, with limited education belong to groups that are hindered from investing time for deliberation. Attitudes of distrust towards institutional actors or lack of recognition of the issue at hand as relevant to their everyday life are also at play. Hence, NBCs are advised to design the recruitment stage with a view to these concerns so that diversity is supported.

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⁸ For more details see: Carman et al. (2013).
Self-selection whereby participants volunteer for the deliberation is also a popular method. According to this, further to their application participants are screened for meeting several socio-demographic or other relevant criteria. In a possible disadvantage, this can result in a non-probabilistic sample that does not accurately represent the population. On the upside, having a group of people who are committed to partaking may be of essence in the occasions where deliberation is on-going.

While the two previous methods aim for representativeness, NBCs could alternatively look for participants who are directly affected by the issue that is up for discussion. Recruiting with the help of representative agencies or advertising in specific constituencies is bound to be more productive in these cases. The enlisting of other actors in the recruiting process, which can also be professional recruiters, can prove helpful when it is hard to reach a targeted population. These collaborations can also be founded as partnerships with longer periods of attachment to the project between the two parties.

In the cases of purposive sampling, participants are screened with a number of considerations in mind, including avoiding homogeneity in views, extremity of perspectives, or stakeholders who represent interest groups. It is assumed that citizens with no preformed convictions in terms of the issues in discussion are less likely to resort to rigid argumentation. In addition, when the issue requires a level of basic understanding, participants can also be screened for competency.

Regarding the incentives offered to participants, it is common for them to be financially compensated. Nevertheless, for participants, this has more symbolic than pecuniary value. For self-selected individuals, a more efficient incentive is the knowledge that their input would have influence on policy-making. NBCs should therefore make this information central during the process of recruiting.

Several of the deliberative methods distinguish between educational and discussion components. During the former participants are given accurate and balanced information regarding the main tension and the associated perspectives. Apart from written material, this can also be based on expert testimony, or visitation of a relevant site. The information should be communicated in a non-technical language that is easy to understand and related to common everyday experience. It should be noted here that the educational component is not specifically tied to deliberation, but can be an autonomous activity of committees. Some NBCs have already active educational projects that are targeted at younger citizens who are still in education. Through collaborations with national and local authorities, several initiatives look to inform students in high schools or universities on bioethical issues.
GENERAL CONSIDERATIONS

In conclusion, with regards to the operationalization of the deliberative process NBCs are advised to explore the literature around the methods summarised above and tailor them to their needs and circumstances. The following practical points might also be of help during the process:

CLARIFY GOALS

The outright crystallization of the goals of the deliberation will help NBCs to design an effective deliberative process. Furthermore, it will increase the usefulness of the outcome towards policy recommendations. In terms of making the public aware of the committee’s work, informing the citizens of their potential contribution to policy is very important. The meaningful participation of the lay public is directly related to the legitimating aspect of deliberation.

LINK GOALS WITH TASKS AND METHODS

Deliberative methods are of varied operational value depending on the issue that participants discuss. The role of experts, educational material, segmentation in sub-groups, their size and session length can affect the quality of deliberation and results. NBCs are therefore advised to consider their features in line with the tension to be explored and their goals.

Large groups are generally considered to be more representative of the population. Nonetheless, less time is afforded to individuals to express their points of view, and they are often broken-up in smaller deliberative teams. When choosing a method, the combination of the factors of recruitment and cost is also to be strategically considered. The length of sessions is also an issue that affects quality. Longer sessions have the advantage of allowing participants to develop deeper understanding of the issue, as they allow for diverse perspectives to emerge gradually. On the other hand, they require significant time investment, which can be discouraging for interested participants.

OPEN UP THE PROCESS

Transparency of the procedures is crucial for the legitimating power of deliberations. NBCs can control for transparency with the careful selection of facilitators. It is preferable

9 A starting point can be Participedia.net, an independent website on participatory methods.
that these can be individuals with no policy-making ties. In terms of the engagement of participants, it is advised that this commences early in the process so that they all start deliberations on equal terms.

**CHOOSE THE FACILITATORS CAREFULLY**

The facilitator is a role where the decisive criteria are not institutional membership, but rather a combination of mediating skills and adequate knowledge of the issue. Facilitators should aim to establish an open and safe climate where participants engage in reason giving, in a mutually respectful, rational manner, enjoying the same opportunities to voice their opinions. It is up to the facilitator to pose the deliberative task to the participants, and should be able to have a relatively good grasp of the issue at hand. It is expected that he/she explains clearly the expectations of the committee to the participants and be amenable to further enquiries. According to the method of deliberation, a number of facilitators may be required to convene several sessions.

**TEST THE INFRASTRUCTURE**

Practical matters regarding the distribution and access of the educational material, and the technical infrastructure of the venue where deliberation will take place should be tested and any issues should be resolved before the procedure commences.
The anxiety that accompanies the introduction of techno-scientific innovation is expressed in the public space. This is a realm in which news organizations are central in mediating events, ideas and attitudes that develop within the social fields. Bioethical issues, as we already have seen, emerge in the public space as controversies, a form that is typically of great news value. The deeper tensions that underlie these controversies are related to the lack of information or legitimation, which, as discussed, overlaps with optimism, often found in expert knowledge and scepticism, which revolves around the citizens’ understandings of risk.

These antinomies are not new in the field of Bioethics; in the introduction to 1978 book *The Swine Flu Affair. Decision-Making on a Slippery Disease*, by R. E. Neustadt and H. V. Fineberg, the then US Secretary of Health, Education, and Welfare, J. A. Califano, Jr., had raised several questions as bioethics entered the policymakers’ agendas:

‘First, how shall top lay officials, who are not themselves experts, deal with fundamental policy questions that are based, in part, on highly technical and complex expert knowledge - especially when that knowledge is speculative, or hotly debated, or when ‘the facts’ are so uncertain? When such questions arise, with how much deference and how much scepticism should those whose business is doing things and making policy view those whose business is knowing things - the scientists and the experts? How should policymakers - and their expert advisers - seek to involve and to educate the public and relevant parties on such complicated and technical issues? To what extent can there be informed and robust public debate before the decision is reached?’

Let us now see how NBCs have answered these questions in practice, by engaging the public and stakeholders. Some of the examples below are not from NBCs. However, they may be useful to NBCs. You will see in these examples how training the public is a major part of public engagement.

1. **Chad’s National Committee on Bioethics**

The Republic of Chad established the Chad’s National Committee on Bioethics in 2010, within the framework of UNESCO’s ABC Project. The Committee functions effectively and has already advised national structures and international NGOs on research protocols.
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In 2017, it deemed necessary to widen its visibility throughout the country in order to further fulfill its mission, and organized an information and awareness-raising seminar. The ABC Project logistically and financially supported this event and an expert from the bioethics committee network advised the Committee on the implementation of the seminar.

Targeting scientific communities, public authorities, civil societies and the general public, the seminar gathered participants from various backgrounds to share experiences and research results. Several members of the Chad’s National Committee on Bioethics presented specific key themes on bioethics, whilst representatives from hospitals and the health sector emphasized on the notion of consent and on other issues related to ethics and to the patients’ rights. Furthermore, some researchers shared their results and analysis with the audience. Participants included representatives from national research structures, representatives of national and international NGOs, Ministries involved in research, and also traditional healers.

The seminar received a wide media coverage, in magazines and on public and private radio, but also on television, in the two official languages (Arabic and French) in order to reach the widest audience possible. A television program was also organized with Electron TV, a TV channel in Chad.

2. Malawi National Committee on Bioethics (NACOB)

Malawi, being a State Party to UNESCO, established the National Committee on Bioethics within the ABC Project context. (NACOB) through the National Commission for Science and Technology (NCST).

In 2017, it organized a training that was followed by a live public awareness panel discussion on Zodiak Radio Station on matters of bioethics. The panel discussion enhanced consciousness of the general public on matters of bioethics. It presented the general public with an opportunity to interact with experts in bioethics live on radio. The members of the public had the opportunity to pose questions and make comments on the subject under discussion to which the panel of experts provided clarifications. The live panel discussion was bilingual (i.e. English and Chichewa). The panellists addressed the following critical questions, among others:

- What is the role of bioethics as a discipline?
- Does bioethics have a potential to accelerate socio-economic development in Malawi as a low-income country?
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• How can bioethics be applied to solve societal challenges in agriculture, climate change, health, education, research, science and technology?

• How can bioethics promote science and technology with humanity?

• How can we harness bioethics as a moral capital and a social comparative advantage for Malawi’s sustainable development within a competitive globalized economy?

• How can bioethics be fostered and mainstreamed across different levels of the Malawi economy?

The panel discussion lasted two hours. A recording of this panel discussion was then made available for future broadcast. A cross-section of members of the general public including members of the press, public agencies, civil society organizations, members of the academia, interest groups and members of NACOB were in attendance, following targeted invitation and public notice that was aired on Zodiak Radio Station. This recording was aired out on public radio a number of times in 2012, 2013, 2015 and 2016. It was then used again in a series during training meetings of stakeholders in research ethics over the period.

3. Mexico’s National Bioethics Commission

Mexico’s National Bioethics Commission has used the radio, the television, the Web as well as various printed media such as newspapers and gazettes, to disseminate its mission and its work (Soberón and Feinholz, 2009). The main objective and the mission of the Commission from 1992 to 2009 were to promote a culture of bioethics. The emphasis was to provide different professional groups and all members of society at large with the elements to be able to identify an ethical issue, how to approach it and eventually solve it. In 2005, a new decree put the Commission under the scope of the Secretariat of Health and granted it technical and operational autonomy, allowing it to become a regulatory agency aimed at promoting a culture of bioethics, encouraging reflection on human health, and developing guidelines for health care, research, and education, through a global, secular, and democratic perspective (de Chavez and Olaiz, 2017).

One example occurred during a highly controversial time in the country, which was fully immersed in a debate on the depenalization of abortion. One of the federal States, promoted depenalization, before three months of pregnancy, provided that women had sound physical, socio/economic or emotional reasons, were given guidance and had passed physical examination.
The Supreme Court was requested to rule if this law was unconstitutional. Society was highly polarized, and the dialogue was quite difficult. Therefore, on 18 April 2007, an article was published in the newspaper *Reforma*, one of major dissemination in the country, to present the reflection of the Mexico’s National Bioethics Commission (signed by the Executive Director and the President of the Council of the Commission) on the issue of abortion. This prompted positive comments from academics as well as from members of the civil society, mainly, thanking a non-polarize and factual text, that allowed for a better understanding of the debate.

The members of the Commission, a multidisciplinary and pluralistic group, from different institutional affiliations, had drafted this article. The article was a consensus text that clarified first the issues at stake. Indeed, it was not depenalization of abortion as such, which was being proposed, but depenalization of abortion within a very specific time period. Then, concise explanation of the whole range of arguments both in favour and against this proposal was provided. Lastly, the article indicated that this debate should be framed according to the political and social structure of the country, meaning, that the Mexican State has the duty to ensure every citizen to be able to live her or his life, according to his or her beliefs.

This article triggered further media attention, and, after its publication in the newspaper, the President of the Council of the Commission was invited to a telephone interview on April 19 of 2007, in the newscast broadcasted on *Radio Fórmula*. At the time, the newscast was one of most popular program in Mexico and was conducted by a very well-known and widely followed journalist. The President of the Council of the Commission reiterated the ideas delivered earlier at a University. On April 15 and 20, he also appeared on television.

At the request of the Rector of the National Autonomous University of Mexico (UNAM), the *University Gazette* reproduced the entire text of his intervention on April 23. Moreover, the Executive Director of the Commission participated live on *CNN* in Spanish, also on April 23, reiterating the importance of identifying central elements of the debate, as well as the arguments that underlie each one. He also stressed the importance of carrying out an informed, ordered and sustained dialogue that takes into consideration all the voices expressed on the subject, which must be respected so that the legislation is consistent with a morally plural society that coexists in a secular State.

Another example concerning the use of social media to inform the society in Mexico is the following. In order to respond to the concerns of society regarding the law initiatives on euthanasia that were being discussed, the Commission considered it appropriate to prepare a document that would help clarifying the concepts related to this topic. Thus, one member of the Board, an expert on the topic, was asked to draft the text, which was then
reviewed and enriched by the full Board. The final version of this article on euthanasia was published on the website of the National Commission of Bioethics, and the newspaper Reforma published an announcement directing readers to the NBC portal.

Likewise, Mexico’s National Bioethics Commission organized the forum ‘Dignified death, a real opportunity’, in response to the concern engendered in society by the proposed law on euthanasia. The forum was held on 25 June 2005, at the General Hospital of Mexico, one of the biggest of the country.

The objective of the forum was to explore, from different disciplinary perspectives, the themes of illness and death. Euthanasia is one of the most complex bioethical issues insofar as it implies a situation in which biological, psychological and social issues converge, at a time when respect of human integrity, search for well-being, and warm assistance in the process as well as in the moment of death must be ensured.

The forum was structured on the biological, psychological, social and bioethical perspectives and included the participation of researchers and health professionals. It was open for the public and free of charge. The auditorium was full. The Commission then published the papers.

4. **Singapore’s Bioethics Advisory Committee**

The Singapore Cabinet established Singapore’s Bioethics Advisory Committee (BAC) in December 2000, with the aim of addressing the ethical, legal and social issues arising from biomedical sciences research in the country. According to the BAC, it is a policy advisory body, not an executive body, and has no supervisory or regulatory power. The guiding principles of the Committee are:

1. Respect for persons
2. Solidarity
3. Justice
4. Proportionality
5. Sustainability

Singapore has a rapidly developing biomedical science sector following the Biomedical Sciences (BMS) Initiative in June 2000, which has the long-term goal of establishing a strong knowledge-based economy.

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The BAC gathers data and information from the international and local community and translates it into recommendations for the national government. In addition to communicating with experts in the field elsewhere, the committee ensures public involvement in the decision-making process, especially regarding new biomedical advancements, by providing them with information in the form of a consultation report. This report is then open to comments from the public as well as organizations for 8 weeks. This period of consultation is supplemented with public dialogue sessions and open forums on the subject under consideration. The BAC uses this feedback to formulate recommendations to the government. Respondents can choose to have a copy of the final report delivered to them. Some of the current projects include Ethical, Legal and Social Issues Arising from Big Data in Human Biomedical Research, Ethical, Legal and Social Issues Arising from Human Nuclear Genome Editing, and Ethical, Legal and Social Issues Arising from Mitochondrial Genome Replacement Technology.

Finally, the Singaporean BAC also sets up public forums for discussions on bioethics and arranges events, past examples of which are a Bioethics Week held in 2015 and a Bioethics Festival held in 2016. An interesting initiative also has been to add bioethics exhibits to a permanent exhibition at the Singapore Science Center for a number of years. Students are also encouraged to participate in bioethical discussions with film screenings and school-based projects.


In November 2007, the Nuffield Council, the independent body that examines and reports on bioethical issues in the UK, published its report on the ethical issues that emerge from the efforts to improve public health. The report documents in detail the consultation efforts of this long-term project that have informed its working parties:

From May to September 2006, the Working Party held a consultation, to which 112 individuals and organizations responded. During the progress of the Working Party, the Council worked with Ecsite-UK, the UK Network of Science Centres and Museums, to develop workshops for young people on the issues surrounding vaccinations. The Working Party provided advice on the content of the workshop materials. A total of 503 people aged 14–19 took part in debates about vaccinations in schools and four science centres around the country between April and September 2006. A summary of the discussions was provided to the Working Party in October 2006.
A number of stakeholder meetings were also conducted in 2006:

1. Meeting with individuals and organizations with an interest in obesity held as part of the third meeting of the Working Party.

2. Meeting with individuals and organizations with an interest in fluoridation of water and fortification of food held as part of the fourth meeting of the Working Party.

3. Meetings with individuals and organizations with an interest in alcohol use, with individuals and organizations with an interest in tobacco use, with individuals, and organizations with an interest in infectious disease.

In order to gain the views of interested professionals, organizations and members of the public, the Council held a consultation shortly after the Working Party was established. This was based on a Consultation Paper that contained background information and a set of nine questions for respondents to answer. The Council sent copies of the Paper to individuals and organizations with an interest in this area, and publicised the consultation through email discussion lists, its website and a widely circulated press release. In total 1,100 copies of the Paper were sent to healthcare and professional organizations, religious and interest groups, academics, medical experts and interested individuals; it was also available online.

In total, 112 responses were received, 57% of which were from individuals and 43% from organizations. Respondents included the following: Interest group or member of such a group; Academic institution or individual; Individual with other professional interest Professional body or society; Health professional Government and NHS bodies and departments; Health-related organizations; Funding bodies; Schools; Companies or organizations with a commercial interest, others.

All responses received were then sent to the members of the Working Party and discussed in meetings. Many respondents agreed to make their full submissions publicly available and their comments can be found at the Council’s website.

At the next stage, a summary of consultation responses has been produced. It outlined some of the key points raised by the individuals and organizations that responded to the consultation. The Nuffield Council received 112 responses in total. The report does not relay all the points made, but rather reflects the opinions expressed and highlights salient points. Because the consultation was open to anyone to respond, rather than being conducted as a survey or poll, the responses cannot be considered to be representative of the population, and should of course not be interpreted as such.
The participants commented on the following issues: Fluoridation of water and fortification of foods; Vaccinations, quarantine and isolation; Smoking; Alcohol; Obesity; The roles and responsibilities of corporate agents in public health; The Role of government or State; The tension between personal freedom and curtailing choice in order to provide public health benefits.; The Factors affecting public health: environment, social and economic factors, lifestyle, genetic background, and preventative and curative health services; Ethical principles: autonomy, solidarity, fair reciprocity, the harm principle, consent and trust.

6. **The Danish Council of Ethics: Educating young people**

The Danish Council of Ethics has set up in 2001 an educational initiative targeted at students. The project, which has been on-going since, is named Ethical Forum for Young People and is designed as a participatory project that educates students in bioethical issues and the democratic process. The relevant Working Group is responsible for the Forum event, and publishes the educational materials, which are available before the event. The education material aims at getting primary school pupils to discuss ethical issues in the classroom as well as at home around the dinner table. The Council publishes an instruction booklet and hosts every second year a youth conference, where 17 pupils discuss positions about the topic raised the specific year.

The booklet can be obtained for free by ordering at the Council’s website (in Danish only). The primary school teachers and their pupils are using the material during the autumn semester, and set the course for a pupil to participate in the Forum in the beginning of the following year.

The Forum is a two-day event. 17 pupils meet and discuss the specific topic. Based on the topic and the position statements, the 17 students produce an opinion on the second day of the event. The opinion is sent to Danish politicians and other stakeholders.

In 2013, the topic of the Forum has been the challenges for young people with mental illnesses. The Council focused on the relations that these young people form, or are deprived of, recognizing the difficulties that they typically have to overcome. The educational material has been sent to elementary schools across Denmark, and has been published in electronic form, including the interviews with the children.\(^\text{11}\)

In 2015, the topic of the Forum has been the ethical questions around birth and pregnancy. Possible discussions can refer to assisted reproduction, the right to know one’s parents, [11](http://ipaper.ipapercms.dk/dketik/DER/2013/Indeellerude/)
foetal diagnosis. The production of the educational material is then enriched by workshops with pupils.

7. Switzerland’s National Advisory Commission on Biomedical Ethics: Informing the public

The Swiss National Advisory Commission on Biomedical Ethics is an extra-parliamentary body, which was established by the Federal Council on 3 July 2001. The Commission’s mandate is to conduct a careful and comprehensive assessment of ethical issues arising in the areas of medicine and healthcare, focusing in particular on new scientific knowledge and technological developments.

According to its 2014 annual report, the Commission engaged in the following activities in order to communicate with the public: ‘A media conference was held on 13 February 2014 to present the Opinion on medically assisted reproduction (no. 22/2013).

As is customary, to accompany its annual two-day meeting – held in Appenzell (Canton Appenzell Innerrhoden) on 23/24 October 2014 – the NEK-CNE organised an evening event for the public, including a panel discussion, on the subject of Culture of death and dying. This event, held in Appenzell’s town hall, attracted considerable public attention; the interest displayed by the audience was overwhelming. The topic was deliberately chosen by the Commission as a counterpoint to the debate on assisted suicide: calls for physician-facilitated suicide often spring from fear of the end-of-life period, and of dependence or helplessness. At the same time, “technical” questions associated with assisted suicide – what is permissible/prohibited? – may obscure a more fundamental human question: How can mortality, leave-taking and death be integrated into life, without this leading to negativity or depression?

An introduction to this topic was provided by the Commission’s Chair, Professor Otfried Höffe. Taking into account the experiences of Dr Karen Nestor (palliative care specialist at St Gallen Cantonal Hospital), Franziska Waber (head of nursing and care at the Evangelisches Pflegeheim Bruggen) and Stephan Guggenbühl (former Appenzell Cantonal Priest), the following questions were then discussed: What is our experience of the care provided for the dying? How has it changed in recent years? What difficulties arise – for the dying and for their relatives? Commission member Professor Brigitte Tag moderated the panel discussion. The event was extensively reported, with half a dozen articles appearing in the local press.

In addition, the Commission and its Chair and members were also present in the media in various contexts throughout 2014. Particular mention should be made of
contributions and interviews on the topics of the culture of death and dying, assisted suicide, intersexuality, reproductive medicine and cost-effectiveness in healthcare.

In 2014, the Commission launched a new website, with its own domain name. While the structure of the site is unchanged and it continues to comply with the Federal Administration’s corporate design, it is no longer part of the Federal Office of Public Health web-site, but has its own address: www.nek-cne.ch’ (NEK-CNE, 2015).

8. US PRESIDENTIAL COMMISSION FOR THE STUDY OF BIOETHICAL ISSUES: ONLINE COMMUNICATION

The Presidential Commission for the Study of Bioethical Issues (the Bioethics Commission) is the United-States advisory panel of the nation’s leaders in medicine, science, ethics, religion, law, and engineering. The Bioethics Commission advises the President of the United-States on bioethical issues arising from advances in biomedicine and related areas of science and technology.

The Commission publishes its work in the form of responses to the President’s requests for advice on a bioethical issue. These are informed by a series of public meetings. In the case of its 2010 publication ‘New Directions: The Ethics of Synthetic Biology and Emerging Technologies’ President Barack Obama asked the Commission to review the developing field of synthetic biology and identify appropriate ethical boundaries to maximize public benefits and minimize risks. The Commission approached this task through inclusive and deliberative engagement with a wide variety of sources, including scientists, engineers, faith-based and secular ethicists, and others who voiced, as expected, sometimes conflicting views on the science, ethics, and social issues surrounding synthetic biology. Through public meetings in Washington, D.C., Philadelphia, and Atlanta, the Commission created a forum for open dialogue to hear and assess competing claims about the science, ethics, and public policy relating to synthetic biology.

Several experts explored potential benefits of synthetic biology, including the development of vaccines and new drugs and the production of biofuels that could someday reduce the need for fossil fuels. Discussions addressed the risks posed by the technology, including the inadvertent release of a laboratory-created organism into nature and the potential adverse effects of such a release on ecosystems. To reduce any possible threat, some scientists and ethicists advised careful monitoring and review of the research.

The Commission concluded that while the technical challenges of synthetic biology remain daunting, the field is likely to become more decentralized, as the relevant tools become
increasingly available and affordable—a change that may pose novel challenges with regard to oversight.

The Commission uses its website to publish its responses, press releases, and educational material. Relevant posts accompany its activities during the process of deliberation and after publication on its blog. Members and staff of the Commission upload material and the public is invited to comment. The public meetings are webcasted and the video is archived for future viewing. The transcripts of the meetings, presentation and educational material are also posted online. Social media (Facebook, Twitter, Storify) are also utilised to inform the public of the Commission’s activities and direct interested citizens to its online resources.

9. France’s National Consultative Ethics Committee (CCNE)

In France, a law to revise the laws of bioethics is voted on a regular basis, the underlying subjects being re-examined by the legislator every five to ten years. The French National Consultative Ethics Committee is called on each occasion to give an opinion prior to the tabling of the government bill in parliament. In 2018, the said national committee organized, before rendering its opinion, the general states of bioethics with a dedicated website (https://etatsgenerauxdelabioethique.fr/).

One month after the end of the consultation, more than 180 citizens’ debates had already been organized in the regions thanks to the relay of regional ethical reflection spaces. In total, there should be 260 at the end of the consultation. 20,000 people will have participated in this process.

In addition, on the dedicated website, in 1 month and a half, 75,000 unique visitors were identified of which 9,700 made a contribution with 24,000 arguments filed and 273,000 votes. The final consultation should reach 50,000 arguments.

The committee also invited more than 330 associations, about fifty learned societies and about ten large institutions to be auditioned. Each must submit a written contribution before a hearing before the committee.

Finally, the committee has also set up a citizen committee composed of 22 members, which will meet during 5 weekends. After a training workshop in the themes of the revision of the laws of bioethics, this committee was called to choose two of these themes on which it will work: it is the end of life / assisted suicide and genomics. This citizen committee will draft three reports, one on the whole process, and one opinion report on each of the two chosen themes.
With all these contributions, the national committee will produce a first summary report that will include numerous appendices and summarize, in a neutral manner, the various debates, hearings and contributions.

Subsequently, the national committee has produced an opinion on certain themes that it considers to be a priority in the revision of the law (CCNE, 2018).

The Chairman of the CCNE stated recently to the French Senate ‘Our opinion is that we must keep this model, without being content with a one-off debate every five years. We recommend to continue the debate and the information on bioethics, during a continuous dialogue with the French society, in the regions (at a local level).’

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12 Available at: http://www.senat.fr/compte-rendu-commissions/20190114/soc.html#toc3
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UNESCO Bioethics and Ethics of Science Section

The Bioethics and Ethics of Science Section reflects the priority UNESCO gives to ethics of science and technology, with emphasis on bioethics. One objective of the Organization is to promote principles and ethical norms to guide scientific and technological development and social transformation.

Activities of the Section include providing support for Member States of UNESCO that are planning to develop activities in the field of ethics of science and technology, such as teaching programmes, national ethics/bioethics committees, conferences and UNESCO Chairs.

The Section also ensures the executive secretariat for three international ethics bodies, namely the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST), the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC).

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