

WHITE BOOK

RESPONSIBILITY FOR PUBLIC HEALTH IN THE LUSOPHONE WORLD

DOING JUSTICE IN AND BEYOND THE COVID EMERGENCY

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FACULDADE DE DIREITO
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COIMBRA



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WHITE BOOK

The Ethics of Public Health Emergency Preparedness and Response

**RESPONSIBILITY FOR PUBLIC HEALTH
IN THE LUSOPHONE WORLD**
DOING JUSTICE IN AND BEYOND THE COVID EMERGENCY

Project Sponsored by the World Health Organization
WHO ERC number - (CERC.0079/ HEG 70)



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LIST OF ABBREVIATIONS

Art. – Article

CDB – Centre for Biomedical Law (*Centro de Direito Biomédico*)

CRP – Constitution of the Portuguese Republic (*Constituição da República Portuguesa*)

EU – European Union

Macao, S.A.R. – Macao Special Administrative Region

PPE – Personal Protection Equipment

WHO – World Health Organization

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INITIAL REMARKS

JOÃO CARLOS LOUREIRO

The White Book now being presented to the public, academic or otherwise, is first and foremost an act of accountability for the results of a research project that responded to a challenge issued by the World Health Organization (WHO) in a pandemic context. The proposed motto for the research was a broad “The Ethics of Public Health Emergency Preparedness and Response”, capable of accommodating bridges with Law. The University of Coimbra Institute of Legal Research (UCILeR) has certainly some experience in this field, namely through the work in Health Law of its researchers in the area of Vulnerability and Law, but also of colleagues from other areas. As a matter of fact, faithful to its strategic project, based in the trilogy - Vulnerability/ Plurality/ Undecidability - the Institute promoted, in April and May 2020, a series of talks with the theme “Pandemic(s), Uncertainty and Law”, with four meetings: I. State of Emergency in Democracy; II. Health Policies in Times of Pandemic; III. Freedoms and Rights in Times of Confinement (Part 1); IV. Freedoms and Rights in Times of Confinement (Part 2). Besides articles by its researchers, published in Portugal or abroad, a volume dedicated to Pandemic and Law has appeared in the collection Societal Challenges and Research in Law.

One should not be surprised, then, by the positive response to the challenge that materialized in the project, funded by the World Health Organization, entitled Responsibility for Public Health in the Lusophone World: doing justice in and beyond the covid emergency. However, it did not do this by shutting itself off, turning the University Tower into an ivory tower, but rather by strengthening the networks that build bridges into the Lusophone world, united by a language that

is plural in its incarnations and re-appropriations. In Africa, we invited representatives from Angola (Armindo Jelembi, also an UCILeR researcher) and Mozambique (Carlos Serra); in Latin America, we invited a solid partner, the Oswaldo Cruz Foundation (Sandra Alves); in Asia, we went to the *Portas do Cerco* to see, through the hand of Vera Raposo, the experience of the Macao Special Administrative Region. Four continents, all ravaged, to a greater or lesser degree, by the pandemic and with disparate means to respond to the public health crisis. In a time of neo-globalization, but in which glocalization is taken seriously, this pandemic proved the differences and inequalities of the world, also in this field. If in the 19th century (the first international sanitary conference took place in 1851) the risks of epidemics significantly drove an International Health Law, in more recent years the development of post-Westphalia governance mechanisms must be underlined. Despite introversion trends in some countries, where an old conception of sovereignty is waved as a flag, revealing excesses of “globalism” (the reduction of globalization to its economic sphere, as Ulrich Beck said), it is becoming clear to many that health, besides being a personal and communitarian good, is also a global public good. It is a matter of responding to the pandemic, and responsibility should not be said in a disjunctive way - either/or - but rather requires an “and”, which brings together state and civil society, national and international and supra-national instances. This period of health emergency has proven that, except for a hermit-like retreat into the desert, no one can be saved alone. To guarantee *immunitas*, we need more *communitas*, a common action, because the pandemic laughs at human borders and does not need a passport to advance.

The openness of the project was also expressed in the multiplicity of knowledge. *Ab initio*, the project had the precious collaboration of a renowned bioethics specialist, Maria do Céu Patrão Neves, Professor at the University of the Azores. Thanks to the network that had been established, jurists and health professionals, academics and practitioners, people from the Health Administration, and representatives of patients’ associations participated. The openness was materialized through the communication, by the hands of Fernando Vannier Borges.

In this “risk society” (Ulrich Beck), the (bio)ethic convoked, without forgetting the differences of national realities, should not lose the global note. In fact, it should be global as to space, speaking of a

“macro-ethics” of responsibility (Karl-Otto Apel), without this being synonymous with the erosion of national states as communities (also of sociality); yet global as to the object, keeping in mind the interaction between men and animals and, in general, the environment, in the time of the Anthropocene.

The project, in the straitjacket of the temporal constraints, did not shy away from some efforts. Not giving in to the temptation of limiting itself to a more or less commented inventory of mobilized norms, a questionnaire was launched, which was based on a platform, taking empirical data seriously. In this way, not only academics, but public servants, as well as health institutions and Non-Governmental Organizations defending patients’ rights and interests, were able to participate in the discussion. Without unveiling the meaning of the results and concretizing the list, it should be said that the answers allowed us to unite on the map all the territories involved - Angola, Brazil, Macau and Mozambique, and Portugal.

In the proposed roadmap, we find the following steps: Maria do Céu Patrão Neves addresses the “Ethical principles and the limitations imposed by States in times of pandemic”; Ana Gaudêncio analyzes the pandemic from the perspective of human rights; Luís Meneses do Vale bridges the gap between Constitutional Law and pandemic; Ana Raquel Moniz addresses the connection between Public Law and pandemic; Inês Godinho focuses on the relationship between Criminal and Sanctions Law and pandemic; André Dias Pereira, Ana Elisabete Ferreira and Carla Barbosa address the theme Patients’ Rights and pandemic. In the final chapter, André Pereira and Catarina de Almeida analyze the questionnaires.

In the genesis of the World Health Organization, in 1948, some perceived utopia in the comprehensive pledged notion of health, which does not confine it to a medical reading, but takes its assumptions seriously. Now, in the context of the pandemic, in circumstances where there is also talk of environmental emergency and catastrophe scenarios are outlined, the theme of apocalypticism receives additional impetus. «Apocalypse», a word with a Hellenic flavor, means, etymologically, to remove the veil, to unveil, and is associated with images of destruction. Despite the pandemic and the millions of lives that have been taken, the sick who experience after-effects, and the people who have seen their daily lives and ways of existence destroyed, we are certain that this

is not the time of the end for humanity, nor will this be the last epidemic. Amidst the pain and suffering, we are witnessing an unveiling: the thesis of the insularity of some societies, particularly those of the Euro-Atlantic axis, does not stand the test of reality.

We began this century with the terror of 9/11 in New York. We experienced in the streets of Paris and London, among many other cities, the fragility of collective security; environmental catastrophe scenarios are being drawn now that, after Hiroshima and Nagasaki, the possibility of unprecedented destruction hovers over humanity. The pandemic helped many, but not all, to think about the fragility of the human condition and the limits of technological capabilities.

Researchers in the fields of Ethics and Law are not expected to discover a drug. Their contribution, illustrated in this work, involves thinking about normative frameworks, identifying rights and duties, assessing the adequacy of norms (material, formal, procedural and organizational) and looking at inter-normativities. The issue of justice, which appears in the title, also deserves special attention when we reach the 50th anniversary of the publication of John Rawls' magnum opus (*A theory of justice*), even if we privilege, as Amartya Sen does, "a realization-focused understanding".

At the time of writing – March 2021 – uncertainty is still high, with a number of differences in access to vaccines; new waves and confinements; economic and social disorder that varies greatly from country to country, given the great disparity of means and possibilities, the weight of the informal sector, social networks, etc. However, having followed the project from the beginning, in the role of UCILeR's Research Area Coordinator, but with the advantage of not having been a participant, in view of the results achieved so far, which are not exhausted in this work, we are already certain that something has been accomplished. Finally, a word of thanks is due to the participants: to those who elaborated the project, to André Dias Pereira who was also responsible for its coordination, and to those who were willing to participate, either by presenting papers or by answering the questionnaire.

It is up to the reader(s), as usual, to evaluate the work and, if they wish, to continue the dialogue. Furthermore, health, as the Constitution of the Portuguese Republic reminds us, in art. 64/1, is not just a matter of rights, since "everyone has (...) the duty to defend and promote it".

1. CHALLENGES OF THE SARS-COV-2 PANDEMIC TO BIOETHICS

MARIA DO CÉU PATRÃO NEVES

A pandemic is always a rare and extreme situation. A pandemic in a globalized, borderless world, such as the one we live in, is an unprecedented situation that becomes even more extreme, calling into question the usual standards of action that then seem inexorably and frustratingly inadequate to the reality.

The first questions that need to be addressed regarding the most appropriate course of action are technical, that is, of an operational nature, concerning the procedures due in the various exceptional situations that are occurring, mobilizing the existing human, equipment, financial and legislative resources. However, all of the available resources tend to run out quickly, given the exponential increase of needs to be met in a short period of time and under a *tremendous urgency*. In such a context of severe scarcity of resources, technical issues quickly become ethical in nature, since it is the balancing of specifically human factors, and in particular the values involved in the various actions available, that become crucial in the decisions to be taken. Subsequently, the intervention of Law also becomes indispensable, in the legal regulation of the aforementioned technical and ethical considerations. This was the most extraordinary reality of the SARS-CoV-2 pandemic, which has now become our own daily reality.

Bioethics, as Ethics applied to Biomedical Sciences from the perspective of society, that is, as Civic Ethics, was therefore called upon to intervene as a decisive factor in the resolution of unprecedented and dramatic human problems, thus recovering and reinforcing the original spirit that had once unleashed it, in the last century, as a transdiscipli-

nary knowledge, and a concrete and effective practice. The intervention of Bioethics, faithful to its identity, was as intense in this pandemic as it was wide in the diversity of issues it envisaged, as well as in the number of bioethicists that it mobilized.

Whilst trying to provide a wide, albeit synoptic, view of this broad action of Bioethics, it is important to systematize it in two major fundamental plans: one at a micro level, centred on the individual, and the other at a macro level, focusing on the shared problems of individuals, on the community. Both unfold into a panoply of issues that we will also seek to systematize in their most relevant impacts.

1. Intervention at a micro level: care for the individual

We have characterized the micro action plan of Bioethics as focusing on the individual. At this level, Bioethics has developed a particularly relevant intervention, both (1) in the definition of criteria for *patient prioritization* for access to health goods and services, and (2) in the legitimization of restrictions to individual civil rights, in favour of public health protection.

It was precisely at this micro level that, in the chronology of the pandemic, severe problems requiring bioethical reflection were first experienced. We refer specifically to access to intensive care and to invasive ventilation, during the first wave of the pandemics in Europe, in March and April 2020, when there were not enough ventilators for all patients. In fact, in the previous weeks, the lack of facial masks, latex gloves, hand *sanitizer gel*, and alcohol for the general population, was already a reality, as well as the lack of *personal protective equipment* for health professionals. Later, with the outbreak of new strains or variants of the virus and the worsening of the health situation worldwide, there was a dramatic shortage of oxygen supplies for critically ill patients, particularly in Brazil, and also a severe scarcity of hospital beds and even of health professionals to provide proper treatment for all patients. More recently, due the urgent need to vaccinate the country, and also the entire world population, the need to define criteria to establish priorities for vaccination has arisen, while not only the insufficiency of the current levels of vaccine production, but also the inevitability of its rationing, have become increasingly evident.

The *prioritization* of citizens for access to health goods requires thoughtful consideration of the criteria to be applied. Although, these should be based on objective analysis of the real public health situation, they do not ignore consideration of factors of a personal nature. This is a huge challenge to the obligation to respect the principle of human dignity, which sets out the absolute and unconditional value of each and every person. At this level, we can consider, as an example, the specific criteria of “age” particularly interesting due to the discrepancy in its valorization in different situations and also to the severity of its consequences in some circumstances. Indeed, “age” has been used to exclude patients from intensive care, even when it is vital for them, when there has been limited capacity remaining; at the same time, age has been used to give priority to vaccination, most particularly when supplies are scarce. In the first case, the justification is that the elderly have a shorter life expectancy (it is important to “save years of life”), applying the principle of utility, or maximum utility for the greatest number of people. However, this principle is valid for the distribution of goods, but not for the exclusion of people, because it would entail their objectification, that is, their consideration as simply objects, as if their worth erodes with time. In the second case, the justification is that the senior’s life is at greater risk (it is important to “save lives”), thus respecting the principle of vulnerability, which implies that care should be directly proportional to the vulnerability of the patient. The inconsistency is evident and the ethical reflection is urgent: if all lives are worth the same, that is, if each life’s worth is viewed in absolute terms, to consider the number of life years as criteria to gain access to healthcare, as criteria to determine whether there should be an attempt to save it or not, stands out as a gross violation of human dignity.

At this micro level, Bioethics has also been committed to the evaluation of public health measures which have had a strong impact on citizens’ individual rights (first generation), particularly on their individual freedoms, the ability of individuals to decide by themselves for themselves, or autonomy, and also on their privacy, or the right to protect personal life. We refer, for example, to the imposition of quarantines and prophylactic isolation, to the identification of all contagion risks, to *mandatory body temperature measurements*, or to the *presentation of a negative PCR test* for access to circumscribed spaces. The fundamental

question that arises is one of ethical legitimacy and legal authority for the limitation of individual rights.

Ethical legitimacy has been argued by the protection and promotion of the common well-being, which can be broadly defined by a set of conditions (tangible and intangible) of shared life that support the development and the fulfilment of the person, singularly and communally considered. Therefore, each citizen is called upon to accept the suspension of some of their rights as an individual contribution to the promotion of the general well-being of the community to which they belong and from which they also benefit. After all, autonomy cannot be seen as an abstract and uprooted concept; it is built and matures in a specific space, time and circumstance, which confirms its inseparability from social responsibility, from the obligation to respond to society's needs and expectations, according to the power each one holds. In fact, nobody lives alone and we all find ourselves embedded in countless networks of dependencies, in an intertwining of rights and duties.

Stretching the same line of reasoning, it could be argued that the entitlement of individual rights could be deeply compromised without the provisional suspension of them and without each one assuming its duties as a contribution to the common good: if infection chains are not contained, all citizens, individually considered, will have an increased risk of infection with unforeseeable consequences. In this context, the authority to impose restrictions on individual rights can only belong to representatives of the common well-being, of the social well-being, that is, public institutions and the government itself.

2. Intervention at the macro level: attention to the community

We have already characterized the macro action plan of Bioethics as focusing on communities and on the problems shared by their members, the citizens. At this level, Bioethics has developed a particularly relevant intervention both (1) in legitimizing restrictions on social rights for the protection of public health, and (2) in the request for international cooperation and solidarity.

Similarly, to what we have pointed out at the micro level as restrictions on individual rights, at the macro level we are also faced with limitations to the entitlement of human rights as the first ethical problem

in the chronology of the pandemic. We refer to the general confinement of the population and the imposition of sanitary fences, the lockdown of almost all economic activities and the imposition of teleworking. Unlike that which occurred at the micro level, in which the negative obligations of the State were reduced in its obligation of non-interference in the private sphere of the citizen, at the macro level the State has positive obligations, that is, it has a duty to build conditions for the social and economic development of the population, which have been severely compromised by the socioeconomic impact of public health measures. Considering that these are second generation rights, which demand for active or positive obligations, States have a duty to implement compensations to mitigate the negative impacts of the pandemic, which should contribute to the legitimization of the imposed measures.

At the same time, it is important to consider that public health measures do not have the same impact on the entire population: for example, there are workers in full-time employment (e.g. health professionals), those who are teleworking (e.g. teachers), those affected by lay-offs (e.g. retail store employees) and inactive workers without recourse to any compensation (e.g. artists). These different social realities show the urgency of implementing the principle of justice as equity, i.e., an equal or balanced distribution of the burdens caused by the pandemic and the compensations attributed by the State. There is yet another important additional problem to consider regarding new ways of discrimination, as has happened with the elderly, locked up in retirement homes and isolated from all family contact, and with the stigmatization of certain groups, as has happened in neighbourhoods with a higher population density, and potentially greater spread levels of the disease, enclosed within a sanitary fence. Equity, non-discrimination and non-stigmatization are rules of the principle of justice, as an obligation to “treat equals equally, and unequals unequally, to the extent of that inequality”, following the principle’s so-called “golden rule”, as formal and abstract as it is broad and consensual.

Also at this macro level, the fundamental question that arises is that of the ethical legitimacy for the reduction of some socioeconomic rights (such as the right to work) in favour of other rights, such as the right to public health. The fundamental ethical principle to be considered is that of proportionality, which requires that State intervention be limited to the minimum necessary and indispensable (in the extension

of the measures and in their length) to guarantee the common well-being; the restrictions and interdictions must be scientifically justified and presented with objectivity and transparency (the way of the intervention must be subordinate and limited to its defined purpose); and the measures adopted must gain the consensus of the population.

Still, at this macro level, Bioethics has also been committed to act within the international relations realm, in the global context, focusing on the third generation of rights, those that concern collective interests, stressing the principles of solidarity and cooperation, among all countries worldwide, and particularly toward developing countries, and sharing benefits from advances in scientific research and for global health. In this context, we can mention realities that seem to be quite different, such as: in the first wave of the pandemic in Europe, the frequent diversion of primary health care goods purchased in China, either breaching sale contracts by being beaten by backstage auctions, or even by the holding of cargo planes and the subsequent theft of the transported goods (State's piracy), where the cargo made stopovers; more recently, and in a much broader dimension, the struggle for the purchase of available vaccines for large sums of money, raising the market price to values that are unaffordable for most countries, as well as their pre-acquisition in volumes that exceed the needs of the national population, leaving other countries with no realistic prospect of being able to vaccinate their own population in the near future. These procedures take place within a rationale based on power, competition and hoarding, which is directly contrary to the logic of ethical action, cooperation and sharing.

3. Overcoming conflicts through conciliation

The enunciation of ethical principles that, at the micro and macro levels, seek to justify and legitimize a wide range of public health and social measures in this pandemic, are not yet sufficient to validate an ethically sound and sustainable course of action. Indeed, the identification and definition of core ethical principles can lead to moral dilemmas, that is, to the conflict between two equally strong obligations that cannot be both fulfilled, at the same time. The choice of a single one, no matter which, will always entail the failure of the other, which, nevertheless, is also an obligation that has to be complied with. We could

point out, as an example, the conflict between individual autonomy and social responsibility, at the micro level, and, at the macro level, the conflict between the right to health, to its protection, and the right to work, to have effective conditions in order to reach a standard of living that ensures the individual and family well-being. Therefore, we also need an adequate methodology to *weigh* the relative importance of the ethical principles in their application to the concrete reality, one that follows a logic of inclusivity, which, at every moment, balances the principles involved, maximizing the values that are in conflict, namely free will, or autonomy, and the protection of public health.

Therefore, the ethical imperative at stake, is not only to identify the structural ethical principles, but also the methodology for their articulation; and the ethical criteria to be established are not essentially of selection, but also of *conflict* resolution, harmonization or conciliation – the latter being obviously a greater challenge than the first. At this level, it is important to:

- (1) objectively and rigorously consider the reality in which it is urgent to intervene (e.g. pandemic);
- (2) evaluate the goodness of the aims of human actions, their goals or purposes (e.g., tendency to eliminate contagions / infections);
- (3) identify the obligations expressed by the ethical principles to be respected (e.g. individual autonomy and common or social well-being) and the potential conflict between some of them (e.g. freedom and confinement);
- (4) consider the moral weight of each of the conflicting obligations (e.g. freedom is compromised in the absence of health) and propose intermediate ways of action that seek to respect both (e.g. more restrictive confinement measures, such as the sanitary fence, for those who represent greater risk of contagion); and
- (5) maintain the commitment in relation to the unfulfilled obligations, reducing the period of non-compliance, mitigating the negative consequences, compensating the burdens, etc. (e.g. lay-off regime or moratoria issuing).

Ethical deliberation will therefore have to be inclusive, requiring consideration of the totality of the values involved, conciliatory, centred on its possible articulation, and comprehensive, keeping the

commitment towards all values and carrying them out to the widest possible extent. This will contribute to building the broadest social consensus, which Ethics requires to ensure its authenticity as a non-violent relationship.

These are the most basic ethical requirements for any and all limitations to be imposed on human rights, to the civil and political, socioeconomic and collective rights.

4. From ethical consensus to legal regulation, to political implementation

Bioethics, in its action at both the micro and macro levels, through the enunciation of the fundamental principles that have to be respected and the imperative of its continuous harmonization, establishes the minimum conditions of ethical legitimacy for the provisional and proportional restriction of human rights, in a time of public health emergency, as well as the authority of the State for the respective legislative initiatives and political implementation.

Ethical reflection must, therefore, be at the base and ground the process of adopting public health measures that, involuntarily but consequently, restrain the rights of citizens and communities. In turn, it is essential that the broad social consensus for which Bioethics contributes, be reinforced by the power of Law. This means that it is important to go further than the recommendations addressed to the individual goodwill, in an inconsequential way, to the establishment of mandatory practices whose contravention is penalized. For example, taking into account the broad consensus regarding the high prophylactic value of wearing facial masks, this measure cannot be just a voluntary undertaking, which would undermine its efficacy; there is a need for it to be made compulsory by a legal power to ensure a real protection of the population.

The sequence from Ethics to Law ensures that the Law cannot be imposed upon the individual and on the community, from top to bottom, in a dynamic of power, which is overbearing and aggressive, but rather that it is claimed by the people, as a desired protection measure, in a process that goes from the bottom to the top. Exceptional legislation in times of pandemic thus responds to the needs, expectations and aspirations of society, with an indelible ethical legitimacy.

In turn, political implementation presents itself as an indispensable and urgent sequence, showing that restrictive measures are not random or potentially easily discriminatory, but are rather an integrated part of a justified, coherent and consistent strategy for the pursuit of a higher and commonly desired social value, in this case, individual and public health.

The ethical process described and its development within the legal and political levels, establish the boundary of legitimacy for the severity of public health measures. As long as these remain within the parameters set out for their proportionality, and their commitment to the speediest and broadest compliance to the universal common moral of Human Rights, they can be considered ethically justifiable.

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