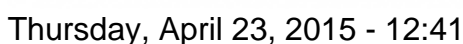




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Ethic [8]

Undoubtedly, epidemics and pandemics are good examples of extraordinary circumstances that may require extraordinary measures. Such exceptionality, however, should not provide an alibi for pandemic planners and

policy makers to ignore fundamental human rights. This is why ethics should always be a key element to be considered when planning a proper response to such global health threats. The Ebola outbreak in West Africa is the last and relevant example of the ethical implications of public health management during an epidemic, due to the many reported cases of stigmatisation and discrimination against the most vulnerable groups of society.

This consideration is at the core of the report produced by ASSET experts, *Ethics, law and fundamental rights* [9], whose purpose is to identify, present and discuss ethical and fundamental rights issues or considerations that arise as a result of contextual or situational factors in the event of a major infectious disease outbreak, notably an influenza pandemic. The report draws on existing evidence from the scientific literature, international agencies' technical reports and policy documents to offer an insight on ethics-related issues and generic approaches

As a first step, ASSET experts analysed the international policy landscape on what constitutes fundamental human rights, both at EU and world level. The Charter of Fundamental Rights of the European Union (CFREU) is the primary legal instrument in Europe that recognises the various personal, civil, political, economic and social rights of EU citizens. It is based on seven main principles: dignity, freedoms, equality, solidarity, citizens' rights, justice and general provisions. However, these principles are not always specific or relevant to public health emergencies. The authors of the report thus analysed the main documents that focused on those fundamental rights from a medical perspective: the WMA Declaration of Lisbon on the Rights of the Patient (signed in 1981), the WHO International Health Regulations (released in 2005) and the Universal Declaration on Bioethics and Human Rights (adopted by acclamation by the General Conference of UNESCO in 2005).

Once such basis were established, the ASSET

experts delved further into the ethical issues and considerations that are pertinent in different phases of pandemic event. Conflicting interests, contextual parameters and critical questions that arise in the course of an outbreak, necessitates the identification and analysis of the various ethical considerations and implications at different phases of a pandemic.

Procedural (how to make decisions) and substantive (what decisions to make) values are discussed. The former ones include recommendations like accountable and evidence-based decision-making, participation, flexibility, impartiality, non-discrimination, inclusiveness. Among the substantive values that are critical in pandemic preparedness planning there are: individual liberty, privacy, reciprocity, equity, trust and solidarity. Restriction of personal freedom, duty to provide care, priority setting and resources allocation, and international cooperation and governance are the main issues with ethical implications that may occur in the context of a pandemic event. The report discussed them one by one, providing some recommendations to overcome related ethical considerations for each of them. In the end, the report presents separately two other issues with implications for pandemic preparedness and response: stigmatisation and vulnerability.

Due to the element of uncertainty and timeliness of actions during a public health emergency, some decisions and measures may come into tension with well-established ethical principles and societal norms, even if these decisions and measures are in accordance with the national or international policies and regulations. Policy and decision makers should take into account ethical considerations to inform and colour all aspects of pandemic planning for preparedness and response. National governments and local authorities should strive to cultivate a culture of ethics, which could be structured on the basis of one of the driving concepts of the ASSET project supports: the promotion of a

bottom-up, participatory and inclusive mechanism with a primary focus on restoring and reinventing trust among scientists, researchers, policy makers and the general public.

Such an approach would inject ethical considerations in the decision-making process, on issues such as the restriction of personal freedoms, the duty to provide care, priority-setting and resource allocation, and international cooperation. The ASSET project can certainly provide this platform and build a collective mechanism (a community of practice) in which fundamental rights issues and ethical considerations in public health emergencies could become issues for open deliberation with all relevant actors from society, whether at local or international level.

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