

ETHICS TO INFORM DECISION-MAKING

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Ethical considerations are an important part of decision-making processes at each stage of an infectious disease emergency. This chapter introduces the notion that ethical thinking begins with a process of clarification of the values and moral principles at work in decision-making, and evolves a set of procedures to reason morally in each decision-making context. Certain moral concepts are necessary to highlight in the ethics of infectious disease emergencies, particularly ideas of autonomy, beneficence, and justice. The chapter then works through the different phases of emergency response, introducing the key ethical issues and questions at each phase.

Ethical thinking does not provide single ideal answers, but enables decision-makers to identify and articulate the value components of decisions, so as to balance, for example, considerations of individual liberties with public health outcomes in an emergency. Elaborate processes of consideration and consultation are often in tension with the challenges of making critical decisions rapidly and under uncertainty. That is why trustworthy institutions and continued community engagement are crucial, particularly in culturally diverse settings.

The chapter concludes by emphasising the need for ongoing ethical reflection and preparedness to better manage future outbreaks, advocating for a sustained social conversation on the balance between protecting public health and respecting individual rights.

INTRODUCTION

Infectious disease emergencies present many ethical and practical challenges for stakeholders involved in outbreak preparedness and response including policymakers, public health officials, and first responders (1). For instance, as witnessed during the 2020–2023 COVID-19 public health emergency of international concern, very complex ethical decisions and trade-offs had to be made to balance the competing needs and interests of individuals, communities, and societies, especially when faced with a rapidly spreading high-mortality condition, and when speed was of the essence (2). While there could be very good reasons to move quickly to protect the health and safety of the public, in many cases, important questions of ethics seem not to have been considered fully before interventions were implemented. The impact of these interventions may not have been assessed according to how their expected benefits would be distributed or how expected costs are imposed. Those who bear the greatest costs may not be the ones who stand to benefit the most. Public health reasoning alone cannot ethically justify any such distribution of costs and benefits. Even when included, ethics is all too often considered separately from outbreak preparedness and response management rather than as an integral concern (3).

Ethics in medicine has a long history, often being traced back at least as far as ancient Greece with the Hippocratic Oath. Such early articulation of professional values in medicine, dating to before the establishment of the scientific method, stated that physicians should put the best interests of their patients first. Ethical concerns in public health involving blunt and extremely restrictive measures during acute crises outside normal medical practice are also historically familiar. The very notions of quarantine (issued to potentially infected persons) and isolation (ordered for persons known to be contagious) used to control the spread of disease go back centuries, at least to the plague outbreak in the 14th century (3). Duties of patient confidentiality also have early ethical and legal origins.

However, the rise of a more scientific understanding of disease and epidemiology occurred much later in the 19th century, as did the elaboration of professional values in respecting the autonomy of patients with consent to treatments which were physically invasive. The advance of medical diagnostics, vaccines, anti-infective treatments, and health systems infrastructure have themselves created more options for public health decision-makers, raising new ethical considerations. The professional duty to treat patients during outbreaks of known infectious diseases was well-established by the influenza pandemics of the early 20th century. While the regulation of medicines to protect public health is relatively recent and followed the widespread use of harmful products in the early 20th century, more liberal notions have brought about the considerations of further rights and interests of individual patients including privacy rights and the right to fair access to essential medicines.

This chapter seeks to outline what we mean by ethics in general as well as during outbreak emergencies. This chapter also provides an overview of ethical issues at different stages of an outbreak. We further illustrate why it is important to consider ethics as an integral part of outbreak preparedness, response, and management, and show how ethical considerations are contextual and cultural, emerging through all aspects of infectious disease emergencies. Ethics rarely provides black and white answers for decision-makers.

WHAT EXACTLY IS ETHICS, AND WHY IS IT IMPORTANT?

Identifying values

We all bring our own values to the practical decisions we make. A key task for thinking about ethics in outbreaks is to first identify those values which may otherwise be implicit (4). Public health officials make decisions all the time, either as policies or in practice, as individuals or in teams. The values at work may be revealed in codes or guidelines or may be discovered as tacit norms and customs. Sometimes, claims of fact also carry important implicit values. To say the evidence does not support a certain intervention includes evaluative judgements about the intervention itself with an implicit judgement of what balance of risks and expected benefits are acceptable under uncertainty. Ethics requires that these values be made explicit so they can be considered and balanced against other factors in the round.

Defining moral concepts and identifying moral issues

In order to identify values, we need the concepts and vocabulary to articulate them. There are many moral concepts which we might consider more or less important in public health ethics (5). These include liberty or freedoms which can be thought of as positive or negative. Liberal approaches tend to place importance on preserving negative freedoms to determine one's own conception of a good life, whereas many non-liberal approaches are not propagated by a leader or an ideology but are part of a society's value regime (e.g., "conformity is

better than individualism”) (2). Related to liberty is the concept of autonomy, which stresses self-determination and is often respected through informed consent, especially to physically invasive treatment. To be able to make autonomous choices, one must have enough information on which to base a decision, be capable of understanding the information in whatever form, and weigh that information in the balance to reach a decision which is not coerced by others. Coercion can occur through obvious mechanisms such as brute force or threat of sanction, or more subtle use of deception or manipulation (e.g., inducing fear). Adults not mentally competent to make decisions may need a surrogate or representative to do so on their behalf. Children are often thought to be vulnerable and even if relatively mature and apparently capable, they deserve special protections (2). Collective decision-making requires each individual in the group to consent, while participative decision-making can be more consultative, tolerating individual veto. Solidarity is a term used to connect people to a cause or situation to show collective support and is different from shared or joint decision-making.

Traditional duties of beneficence and non-maleficence are ways of describing obligations around calculating and balancing the risks and expected benefits for affected individuals and communities. Justice often requires that we distribute risks and benefits fairly across populations and compensate those unfairly harmed. Methods for allocating resources or social goods need to be rational and may use metrics of cost-effectiveness which underline the consequentialist maxim, the greatest good for the greatest number.

When attempting to treat or prevent a new disease, different types of uncertainty are compounded. The precautionary principle advises against introducing new technologies or treatments until their safety is proven, placing the burden of proof on the developer. However, during an emergency, this principle is often challenged due to the urgent need for solutions. Risk profiles change in emergencies, especially for novel pathogens, due to the overall learning as well as treatment availability and evolving natural or vaccine-related immunity.

Those who are not themselves healthcare workers (HCWs) should recognise that professional duties of care are more stringent than the everyday duties held by the general public, and these duties can vary based on the specific roles of public health and medical professionals. These professionals have distinct responsibilities, and their decision-making processes are held to high standards to avoid negligence. Negligence occurs when a decision-maker fails to meet the expected standard, resulting in harm to individuals or populations. Ideas of wrongdoing tend to focus more on actions taken rather than omissions, though failing to act can also have severely negative consequences.

Reasoning about moral concepts to resolve issues

Armed with moral concepts such as those above, we are now able to identify some of the moral issues in decision-making in public health. A decision whether or not to isolate a patient will require considering the values associated with the patient’s liberty and possible containment in hospital, their autonomy in agreeing to diagnostic tests and treatments, privacy rights in keeping their medical history confidential, and informing the public. Public health needs are primarily designed to protect others so they must be weighed against the rights and interests of the individual. These issues can usually be resolved through different methods although the answers may vary with cultural norms and contextual features such as the severity of the disease. Dilemmas are not, by definition, issues which can be definitively resolved. This chapter, therefore, seeks to give a descriptive overview of the ethical issues involved at differ-

ent stages of outbreak response, and what methods are used to reach ethical decisions about those public health interventions, both singly and in combination. A review of the many arguments used to support different positions is outside the scope of this chapter.

One method used to think about ethics is moral philosophy. As a discipline, it seeks to clarify and refine moral concepts and drive systematic thinking about the questions over what one should do or the kind of person one should be in any given circumstance. However, ethics in practical decision-making can never be a straightforward application of any moral philosophy (6). There will always be imperfect information, room for interpretation, and implementation of principles in context, even if the principles themselves are considered universal. The real world is messy and multiple ethical issues may interlock and interact at any one time with no agreed universal answer to resolve them. Notwithstanding these challenges, the values guiding decisions and the moral concepts used to think about and resolve issues must be explicit. Other methods used to consider ethics are through laws, regulations, and empirical study as outlined below.

Laws and regulations

The legal rules which protect individual liberty, autonomy, and privacy may be very different in liberal compared with communitarian or patriarchal societies. Yet, under international organisations, some shared values have been agreed and background working assumptions made. Indeed, the United Nations (UN) Universal Declaration on Human Rights (UDHR), adopted in 1948, was a milestone in international relations, laying out a common legal standard for all UN Member States (7). We will consider specific human rights concerns as they relate to outbreaks in due course.

Empirical ethics

Ethics also have an empirical dimension, in the sense that we could simply ask people about their moral compass and conscience in different contexts. Such a consultative or participative approach to ethics resonates well with the moral philosophies behind the legal human rights instruments (8). Such an approach to decision-making seeks to be more inclusive of those previously disadvantaged or marginalised and helps increase awareness and engagement with public policies (9).

Developing an African-centred ethics framework

Following the West African Ebola crisis in 2014–2016, it became clear that different external researchers resolved the ethical issues associated with clinical trial designs in different incompatible ways. The U.S. favoured choosing a few drug candidates and evaluating them through placebo-controlled trials, while the U.K. was more pragmatic and favoured small screening studies of more candidate medicines to identify large effect sizes before considering large trials of the more promising candidates. The U.K. approach featured different trial designs to provide wider access to known active medicines.

The outbreak was over before definitive results were gained for science yet provided the groundwork for clinical trials in later outbreaks in the Democratic Republic of the Congo (DRC). In order to guide future consideration of ethics within cultural context by those directly affected by the diseases, members of the European and Developing Countries Clinical Trials Partnership (EDCTP) funded the PANDORA-ID NET Consortium and worked with the newly created Africa Centres for Disease Control and Prevention (Africa CDC) to support the creation of an African-centred ethics framework for outbreaks of emerging and re-emerging infectious diseases. Considerable effort was put into convening a group of researchers, members of ethics committees and regulators from the central region, during these later outbreaks in the DRC to consider the ethics of research, especially of monoclonal antibodies. A working group comprising African bioethicists then wrote a culturally authentic and participative framework whilst acknowledging diversity across Africa. Extensive consultation was done in different African settings, including amongst public health researchers, first responders, and members of research ethics committees, to create a set of cultural values to guide research (10).

Ultimately, we might find that we should set somewhat modest aims concerning ethics in outbreaks. It may be possible to reach only an operational consensus on what values should underpin morally acceptable trade-offs or strike apparent compromises in collective negotiation. We might agree on which interventions are acceptable and yet disagree over the underlying moral reasoning. As a result, many codes of ethics will outline certain principles without wider philosophical theories and will provide general guidance over the detailed task of implementation over many different types of cases. Indeed, the major ethics codes lay out operational principles. With the help of academic and operational ethicists, the World Health Organization (WHO) has also issued ethics documents in many areas of ethics and global health with an associated training manual (1,11). While these codes may change over time, they can help describe expected norms for decision-making, have huge symbolic moral salience, and help foster public trust in decision-makers. However, ethics codes cannot cover all the ethical issues which can arise in practice, nor can they offer the fine-grained guidance needed to resolve every case.

Ethics consultations and committees

The COVID-19 pandemic also saw a rise in the provision of ethics support or consultation with ethicists as knowledge brokers or advocates of policies with some perceived moral authority and apparent expertise (12). With the values of people (including ethicists!) themselves potentially being so diverse, it is worth clarifying what expertise was sought and how it was selected in individual cases. The aim of such facilitative exercises may have been less about providing an ethical answer to given questions, and more to help decision-makers explore all relevant avenues and expose possible consequences, intended or otherwise, of different courses of action. However, the responsibilities and liabilities usually still lie with the decision-makers themselves.

In some areas of public health and medicine (e.g., research), ethics committees are well-established structures, with agreed international and domestic standards of practice, often

required by law (13). Constitutions, memberships, and remits can vary but the key idea is to provide an independent opinion on research based on diverse experiences, backgrounds, and expertise to mitigate against a researcher's potentially conflicting interests, minimise risk/harm, and protect research participants from exploitation. There is usually a lay contingent included to offer a counterbalance to professional researchers. Such procedural review takes international and domestic laws into account but cannot be considered substitutes for community engagement or wider public consultation over controversial topics.

All the pillars of outbreak response (**See Chapter 1, Introduction**) will raise ethical issues and draw on the previously mentioned concepts in different ways. Some of the activities and topics have been considered by the WHO Ethics Unit, and others through academic publication or media commentary. However, there are some issues which still need careful thought. Here we provide an overview of the main ethical issues that influence decision-making in outbreak preparedness, response, and recovery.

The following three sections of the chapter review some of the main ethical issues and decisions corresponding to the different stages of infectious disease emergency response. In most cases, such a rapid survey can only identify the issues. In many cases, other chapters include the relevant ethical reasoning on key topics and are cross-referenced.

ETHICS IN PREPAREDNESS AND PREVENTION

Under International Health Regulations (IHR), governments are obliged to invest in systems designed to pick up a seeming needle in a haystack just in case an outbreak ensues, as an outbreak always carries the potential of leading to a severe pandemic, no matter how rarely. In addition, the IHR embrace human rights, providing common ground for all Member States. However, human rights thinking fundamentally concerns the relationship between individuals and the nation state, making wider concerns of international distribution and transnational solidarity more difficult to address. Assistance from the international community to countries less able to devote resources to preparedness is still a source of ethical debate and is highly political (14). Past public health emergencies have seen existing global inequalities become entrenched due to restrictions in vaccine sharing, patent waivers, and diagnostics, as well as research and development infrastructure. As a result, there is growing recognition that there should be more capacity and expertise to prepare for and manage outbreaks *within* developing countries, to redress such global injustices (15). For example, The Nagoya Protocol restricts how biological samples can be lawfully shared internationally, protecting developing countries.

Early warning systems rely on sustainable community engagement (16). However, attempts to change risky behaviour against cultural norms or sensitivities can be counter-productive as new cases may be hidden from officials for fear of reprimand or social stigma (17). Furthermore, without support and resources for day-to-day living, tension and violence against officials could occur when they attempt to quarantine cases and isolate contacts.

Human rights thinking cannot adequately address many emerging and re-emerging infectious diseases which are zoonotic in origin. Ecological studies are providing more data on how to identify potential hotspots for zoonotic disease—especially when they are re-emerging—so that the surveillance of humans and animals can be more targeted (16). However, there has not been sufficient attention paid to our responsibilities towards animals during outbreaks of infectious diseases with zoonotic and pandemic potential. An approach in high-income

countries is often to simply protect or cull groups of animals and compensate any affected animal owners (18) (**See Public health crisis associated with variant Creutzfeldt-Jakob disease**).

Realising that emerging diseases of zoonotic origin may pose global risks, there has been some international support for One Health surveillance in certain developing countries (**See Chapter 13, One Health**). At the same time, there can be reluctance to intervene early when there are strong economic and cultural interests at stake, for example, in maintaining the international meat trade or respecting religious norms in diets (17).

Public health crisis associated with variant Creutzfeldt-Jakob disease in the U.K.

The emergence of variant Creutzfeldt-Jakob disease (vCJD) in the U.K. was linked to cows given contaminated feed. Considering the importance of the meat industry and beef exports, it took significant time to properly investigate and take correct measures for what was known to be poor farming practices and meat processing. The public was consistently, yet falsely, reassured by politicians that consuming beef was considered safe. By safe, however, they meant “safe enough” from a policy point of view accepting a certain level of risk to some. Once there was direct and unequivocal evidence that the human disease was caused by eating beef from diseased cows, the public health approach had to change, both in terms of messaging and industry practices. Meanwhile, other countries cancelled import contracts and started to ban donations of blood from U.K. residents. Between 1996 and 2024, 178 people died from confirmed or probable vCJD, while over four million cows were eventually culled to prevent the spread of Bovine Spongiform Encephalopathy (BSE). Many more people were expected to develop the disease which has a long incubation period.

Basic research and building community trust

It is certainly possible to design response programmes ahead of public health threats, to support decision-makers as and when needed. However, there is no substitute for developing sustainable partnerships with communities and building trustworthy institutions to quickly mobilise effective and ethical responses should the need arise (19). For example, public health interventions invariably require population endorsement especially when carried out in deprived areas with populations who have recollections of past abuses and historic colonialism (16). It is never too early to improve levels of trust (**See Chapter 33, RCCE**).

ETHICS IN OUTBREAK RESPONSE

Risk assessment and strategy

Even with data from early warning systems, it can be difficult to judge when to act and what strategy to utilise. The true severity of the threat may not be recognised until there is too much community transmission to be able to implement standard contact tracing programmes. A fundamental decision in such cases is whether to let the virus spread unchecked to result—ultimately—in herd immunity from natural infection. Herd immunity is the indirect protection offered after a certain percentage of the population becomes immune. These decisions are based on the severity of the disease and speed of spread. Early

models attempt to predict case fatality rates and agree on a threshold. The level of protection conferred by herd immunity must also be well understood, and this is unlikely for emerging diseases. As there is generally no consensus on how many deaths are acceptable, we often look to other endemic diseases for suitable reference points.

Cost-benefit assessments compare the consequences of intervening or not, while other approaches may better account for the idea that negative consequences may sometimes be considered more blameworthy than failures to act (or acts of omission). Negative consequences may also be distributed in ways we consider to be unfair, not reflected in a straightforward cost-benefit assessment. To compound this bias, the precautionary principle requires innovative technologies to be tested for safety before they are made widely available, whatever the prevailing need. Notions of negligence, however, judge both acts and omissions alike in preparing protocols and plans against a reasonable expected professional standard for decision-making.

Knowing where to turn for advice in a crisis is hugely important and it remains good policymaking to draw on diverse expertise and experience. Consulting a wide panel of ethicists can help open possibilities and check assumptions.

Contact tracing and privacy

In an effort to reduce transmission or control the spread of disease, the standard approach is to target contacts of cases for intervention. The principle of proportionality is key so that the severity and intrusiveness of the interventions are in proportion to the threat (20). This principle involves choosing the least restrictive method to meet the same overall objectives. Such methods may involve simply using and sharing the personal data of individual patients as part of routine surveillance programmes for possible targeted interventions later. Contact tracing, for example, monitors potential spread, warns the individuals concerned, and should offer methods of mitigation. The individuals concerned may have no choice over the use of personal data for public health purposes, yet their rights and freedoms are otherwise intact. Mandatory testing of those known to have been exposed may be required when there are no less intrusive measures available and the public health threat is severe enough (21). Necessary measures to enact such policies include a data sharing infrastructure and systems for making diagnoses notifiable to authorities often required by law when the disease is not so stigmatising that patients are dissuaded from seeking medical help.

Closing national borders

During pandemics, the decision whether and when to close national borders to international travel has major implications for economic activity and can ultimately do more harm than good. However, the COVID-19 pandemic has shown that the economy could be protected only through protecting public health. Some countries might close their borders to try to keep a pandemic disease out rather than in.

Physical distancing, quarantine

In all outbreaks, the use of quarantine is arguably one of the most drastic public health measures. It is coercive as it restricts the freedom of movement. It is universally agreed to be morally justifiable only in the most extreme circumstances when no other less restrictive measures would be effective (21). Despite its severity, it can be justified by the most

liberal accounts of the state, which allow or require state interference to prevent a patient from severely harming others. This is called the harm principle (22). Over centuries and until today, this is a commonly agreed practice during the early treatment phase of patients with tuberculosis.

During the COVID-19 pandemic, most of the world became familiar with restrictions on liberty in one form or another, either for targeted communities or across mass populations, to reduce the spread of the SARS-CoV-2 virus. These restrictions—in the form of lockdowns—were designed principally to better manage surge capacities of the health services. With a virus able to spread from person to person asymptotically, restrictions of movement, especially those enforceable by the state, are more difficult to justify using the harm principle alone. We can then appeal to thresholds of probabilities, severity of harm, and collective responsibilities or solidarity. These approaches are philosophically debatable and culturally relative if intuitively morally acceptable in some cases. Communities or states that do not endorse liberal values will generally be more favourable to such restrictions.

Other ethical concerns for the most drastic and blanket measures weigh the consequences of such measures, not all of which can be foreseen. In many countries, lockdowns had unfortunate and unintended consequences, particularly for marginalised populations with limited access to resources (23–24). Additionally, the long-term consequences of lockdowns on human rights, economic development, and social cohesion must be carefully considered. The debate on the ethics of these lockdown decisions continues to reverberate.

The doctrine of double effect (25–26) provides a framework for evaluating morally complex actions like lockdown orders, which bring both intended and unintended consequences. According to this doctrine, an action can be morally permissible if the intended effect is good while the unintended effect may be harmful, but not intrinsically evil. Many lockdowns will have been ethically justified by the application of this doctrine.

The full consequences of the COVID-19 lockdowns are only now becoming clearer, with many countries seeing additional deaths due to other diseases left untreated, delays in diagnoses, and a rise in domestic violence (27) (**See Chapter 23, Maintaining essential services**). However, the number of fatal accidents was likewise reduced. The consequences of quarantine without maintaining social security networks were clearly dire for many of the already disadvantaged (28). Some governments did not implement official lockdowns, perhaps because of the lack of government social security cover, meaning that those at high risk of severe COVID-19 (e.g., pregnant women) were still expected to go to work, often using public transport with little or no personal protection (**See Chapter 32, Protecting the vulnerable**). Entitlements to essential resources to maintain life were not met in many cases.

Conflicts, communities, and communication

Much of the previous research on health and risk communication in academic social sciences foretold ethical issues which arose later in the COVID-19 pandemic especially in relation to social or behavioural issues such as vaccine hesitancy (29) (**See Chapter 29, Vaccine implementation**). Honest communication about uncertainties and trade-offs is required. Any strategy which relays values inherent in policies as indisputable facts to sell them or manipulate people rarely pays off in the long term (30). Deception or misinformation is coercive. Without checking, informational manipulation, such as emphasising benefits and downplaying risks or uncertainties, may or may not be deceptive to motivate or change behaviour.

In addition, using risk communication to instil a culture of fear as a political device for control often leads to stigma and unintended consequences, as seen in the early HIV/AIDS campaigns (31).

Conveying science to some communities, especially those that do not have a clear perception of risk, can bring about some issues. This creates challenges in discharging duties of truth-telling (2). Generating rapport alone is not ethically sufficient to create trusting and trustworthy relationships. The methods for mobilising communities themselves can involve treading a moral tightrope. Tactics such as enlisting and employing a member of the affected community to persuade others to comply with the proposed public health measures simply because this person is trusted by them may be common practice and can be seen as a shortcut to success. For example, community engagement for clinical trials has sometimes been used merely to maximise recruitment rates without necessarily examining understanding and voluntary consent (32).

The rise of digital health

Telemedicine is increasingly being used to facilitate communication at a distance with the hope of improving access. However, there are ethical issues in rolling out telemedicine and include the development of suitable capacity, data protection, security, and sharing agreements. Over-reliance on telemedicine may disadvantage those who are not digitally literate or do not have access to equipment or the internet. If so, it only reinforces inequalities. But this concern alone is not a sufficient reason to deny everyone access to such facilities, to 'level down' rather than to work towards universal coverage.

Ethics in research and clinical practice

For outbreaks of emerging and re-emerging infectious diseases, all types of research, from basic to the behavioural sciences, are needed. While the ethics of animal experimentation and clinical research are well-trodden areas, outbreaks create unique difficulties (13). In the context of a pandemic, proper coordination is needed to avoid a situation where numerous small clinical trials compete for research participants. Standard principles of research ethics include the need for the assessments of risks and benefits to discharge the duties of non-maleficence and beneficence, respectively, independent checks by research ethics review, and consent where possible. All these requirements may be difficult in practice (13) (**See Chapter 18, Research to inform practice; See Chapter 27, Research for therapeutics**).

There are currently two competing approaches to clinical research strategies for therapeutics (**See Developing an African-centred ethics framework**). The first is to evaluate very few candidate therapeutics in placebo-controlled trials to reach definitive results as quickly as possible (33). The second is to cast the net wider to screen candidates through smaller observational work first and only begin large RCTs once candidates show clinical promise (34). The type of research and development (R&D) strategy adopted has major implications for what investigational treatments patients can try and how outcomes are monitored over time. Research ethics often rest initially on assumptions about and disagreements over how medical science can maximise social value. **See R&D strategies for clinical research and options for patients** for how the choice of scientific methods in clinical research can impact the treatments available to individual patients.

R&D strategies for clinical research and options for patients

Early in the COVID-19 pandemic, when the WHO convened its first meeting of experts to agree on a strategy for R&D for therapeutics, there were many more candidate medicines than could feasibly be evaluated in the SOLIDARITY study, a large pragmatic platform RCT which used adaptive ratios so patients had more chances of receiving the more promising treatment of the moment. At the time, there was little understanding of the disease. Some candidates were initially excluded but later found to be useful for severe disease once COVID-19 was better understood. In the beginning, it was not clear whether dexamethasone should be included at all, yet it turned out to be definitive, at least in certain high-income hospital settings. Additionally, tocilizumab, first developed for the treatment of overactive immune reactions and licensed for severe rheumatoid arthritis, was later found in smaller scale trials and early access schemes to be beneficial in some cases. Hydroxychloroquine was initially thought to offer some antiviral action at high doses despite possible adverse effects and so was included and mistakenly used widely outside clinical trials, despite evidence that it could not target the original virus in human cells, but only in African green monkeys. With more understanding of the virus and the disease, it was clear that antivirals are needed early in the course of the disease, yet they were pitted by randomisation against treatments for severe symptoms, possibly after the virus had begun to clear. A strategy which prioritises large RCTs while excluding observational work may be unable to offer the maximum number of individual patients the best possible combination of treatments for their particular stage and set of symptoms (35).

Protecting the healthcare workforce

Procuring adequate personal protective equipment (PPE) was an issue during the COVID-19 pandemic. However, healthcare staff also face other risks, including safety in the field (36). First responders may be received with suspicion and hostility by communities they are investigating, as was seen during Ebola outbreaks in socially unstable contexts in the DRC.

Many health professionals had not seen death on such a scale and were traumatised during the COVID-19 pandemic (37). At the height of the surge in COVID-19 patients, clinical ethics committees were helping record the context within which staff were working and documenting the impact of scarce resources. Without reassurances over professional indemnity and full recognition of the context, staff may become increasingly concerned about their liabilities and may seek advice from clinical ethics committees where they exist.

In addition, HCWs are almost universally considered a priority population for vaccination to safeguard response capacity (20). As a result, HCWs are often asked to participate in research (often clinical trials), though this participation raises questions on how trials are designed including:

- what is the expected exposure to the virus, and under what background working conditions and policies which may be more or less protective from the virus?
- what other diseases are circulating which may seem more or less severe?
- what other surveillance and intervention measures trace and reduce transmission of the virus?

There has been much debate over intended and unintended consequences of policies that make vaccination mandatory or require it as a condition of employment (38). Disciplinary measures or sanctions were sometimes applied to persistent refusers who were thereby deemed unfit to work, especially in patient-facing roles. Such sanctions may have been applied without exhausting alternative measures and exploring the reasons behind reluctance or hesitancy. In some countries particularly short of staff, HCWs may be required to work even when ill.

Human challenge studies

To speed up research into vaccines during COVID-19, many young people were willing to undergo challenge studies as they had a lower risk of severe disease from the virus yet bore the brunt of blanket restrictions on liberty. The acceptability of risk in research is often a matter of referencing other accepted activities to test consistency.

Mass and emergency vaccination programmes

The ethical issues raised by particular vaccination programmes designed by governments and health officials hinged critically on the wider response strategies, other public health measures being used, and the background conditions of the populations affected. In some countries, vaccines licensed for emergency use were widely distributed to release populations from measures which restricted freedom of movement. The ethics of vaccine passports may simply be applicable only in contexts where social restrictions on liberty are relatively accepted. Vaccine passports to enable travel and interaction with others promised a controlled and possibly incremental exit from a full lockdown. However, there could be objections to the policy on the grounds that it maintains state interference on liberty and encroaches on privacy rights irrespective of risks individuals pose to others and what level of risk people were willing to accept. Some established vaccines for endemic diseases become routine, including for people lacking mental capacity as it may be considered in their best interests as a member of a social group to reach a threshold of herd immunity.

Distributive justice and global health

There continues to be concern for justice in the distribution of risks and benefits of research in global health following vaccine nationalism and the role of commercial sectors in upholding patent protections for profits (27). In many respects, highly valuable innovations developed by the private sector always rest on prior public sector funding. We should be able to factor in how different measures affect existing inequalities to better establish fairness in these calculations.

Dealing with death

One of the most challenging aspects of an outbreak response is dealing with death. During the West African Ebola crisis, establishing a practice of safe burials was key to reducing disease transmission but sometimes required an ethical justification to override cultural norms without community agreement or against their wishes (28). Over time, though, compromises through negotiation may be reached to respect all parties. How we deal with death is inevitably symbolic. During the black death, many bodies were buried in mass graves but pointed in a certain direction in respect of religious beliefs (3). During COVID-19, many hospitals did

not have enough body bags to maintain usual practice and pits for mass graves and funeral pyres were reported across the world. Funerals were restricted and social distancing rules applied (39).

ETHICS IN RECOVERY

Establishing a new normal

The easing of restrictive emergency measures can occur in two incubation periods after the last case. In the case of endemic conditions, the end of the emergency is based on epidemiologic and immunologic factors which represent a threat reduction. Relaxing measures can be done incrementally to test each singly before life can return to some semblance of normality (40). Restrictive measures that are extended beyond this point become draconian.

However, the ethics of measures associated with learning to live with diseases which are becoming endemic can itself be difficult. Restoring a liberal order as soon as possible may be more pressing for some countries than others. It may simply involve accepting a certain expected death toll for the sake of regaining freedoms. Reducing the requirements to test and isolate are further indicators. Nonetheless, some diseases cannot be tolerated in human populations as they are too serious, with high case fatality rates, and are too contagious to let loose. In such cases, a policy of elimination may need to be maintained. The harm principle introduced earlier is key to assessing the ethics and legitimacy of such restrictive measures.

Extended monitoring and further research

There may need to be some continued monitoring for epidemiologic and genetic trends along with research into the long-term effects of a disease and to refine therapies, while keeping abreast of trends in case mix and management. Hospitals will still need to address the infection control policies they adapted in the emergency and to determine when, whether, and how they will revert. Booster vaccines may also be needed for staff.

Towards personal responsibilities

A new normal may be devastating for those still clinically vulnerable, unable to benefit fully from vaccination, and seemingly all but forgotten. The weight of personal responsibilities in managing risks can be heavy and stigma is hard to shake, isolating and marginalising the vulnerable. Survivors may still be left unable to work and economically dependent on their families (**See Continuing duties of care to Ebola survivors**). Such loss of livelihood could be due to complications of the disease itself, the vaccines or treatment they received, or underlying chronic diseases putting them at an increased risk.

Compensation and catch-up

Dealing with the consequences of outbreaks can be a long process. There is often little compensation for relatives of the bereaved or those injured through vaccination or working in high-risk environments especially without adequate protective equipment. There may be systems failures for which governments should be held to account (41).

Normal life will also require addressing the backlog in deferred medical treatments unrelated to the infectious disease outbreak. Staff may find themselves dealing with the fallout of frustrated populations with a rise in instances of abuse rather than welcome appreciation.

Widespread access to mental health services (**See Chapter 31, Mental health**) may be essential to smooth the way.

Children in many countries which experienced lockdowns will have missed vital schooling and social interactions which may never be fully restored to a level they would have expected if not for the outbreaks and associated public health measures (**See Chapter 32, Protecting the vulnerable**) (42). Intensive tuition during summer holidays and lengthening school days have been considered following COVID-19.

Continuing duties of care to Ebola survivors

Following the Ebola crisis in West Africa in 2014–2016, Ebola survivors faced numerous challenges including the loss of parents or children, the loss of livelihood, social stigma, poor health, and continued surveillance. Mental health support was critical. The offer of vaccination, with a vaccine developed by Janssen and a programme supported by the Innovative Medicines Initiative (IMI), while experimental, was still available. However, it was not clear to what extent public health officials should prioritise continuing the occasional long-term support in specific programmes for survivors when resources are generally scarce, other vital health programmes need to be reinstated, and communities may become dependent on external, possibly foreign aid, especially when they are at odds with cultural and spiritual beliefs. For example, some cultures do not accept that mental health difficulties can be treated by medicine. That stigma can only be addressed with sustained efforts to communicate current science understandings (43).

Finally, the recovery phase provides an opportunity to reflect on what has happened, reassess current and future population needs, and learn lessons to prepare for future outbreaks.

CONCLUSION

Ethics requires that decision-makers identify moral values in their cultural, religious, and political contexts, and seek to intervene in ways that are least restrictive of rights and freedoms as possible while in proportion to the threat posed. The earlier we can establish trustworthy institutions and foster equal and fair partnerships with populations in different parts of the world, the more prepared we will be for future emerging and re-emerging infectious disease emergencies.

The more liberal the rights and interests we embrace, the more ethical issues there are to consider in public health decision-making and the more complicated the balancing of individual interests against the group's public health status becomes. Fairness requires that we prioritise protecting the vulnerable, distributing the risks of research and sharing of its benefits, and treating different cultures with the respect they deserve.

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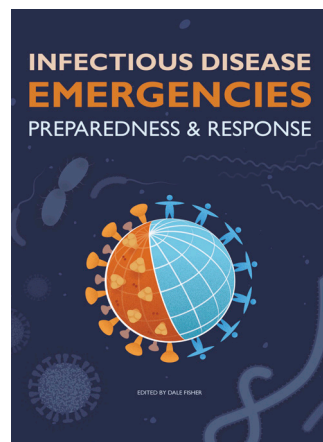
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