STAND ON GUARD FOR THEE

Ethical considerations in preparedness planning for pandemic influenza

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A report of the
University of Toronto Joint Centre for Bioethics
Pandemic Influenza Working Group

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Key Points

- Plans to deal with an influenza pandemic need to be founded on widely held ethical values, so that people understand in advance the kinds of choices that will have to be made. Decision makers and the public need to be engaged in the discussions about ethical choices, so plans reflect what most people will accept as fair, and good for public health.
- The Pandemic Influenza Working Group at the University of Toronto Joint Centre for Bioethics (JCB) has developed a 15-point ethical guide for planning and decision-making for a pandemic.
- The JCB Working Group has identified four key ethical issues that need to be addressed in pandemic planning, and made specific recommendations for each. The four major issues are:
    1. health workers' duty to provide care during a communicable disease outbreak;
    2. restricting liberty in the interest of public health by measures such as quarantine;
    3. priority setting, including the allocation of scarce resources such as vaccines and antiviral medicines; and
    4. global governance implications, such as travel advisories.
- The JCB Working Group recommends that all pandemic plans have an ethical component, and offers the ethical guide contained in this paper for use in

developing such a component.

A. INTRODUCTION

When an influenza pandemic strikes the world many people, ranging from government and medical leaders to health care workers, will face a host of difficult decisions that will affect people's freedoms and their chances of survival. There will be choices about the level of risk health care workers should face while caring for the sick, the imposition of restrictive measures such as quarantines, the allocation of limited resources such as medicines, and the use of travel restrictions and other measures to contain the spread of disease.

Governments and health care leaders have been working on pandemic plans in many parts of the world. However, most of their communication to the public has focussed on technical issues, such how to obtain, stockpile and distribute medicines, and the assignment of duties.

Planners have not generally communicated the ethical underpinnings of their choices in a clear manner. But ethical issues have surfaced in public debates, often in the news media. Should people purchase their own stockpiles of antiviral drugs such as Tamiflu, or should they accept governments' decisions on how to allocate such medications? When medications are distributed, should children come before or after health care and emergency services workers, or decision makers such politicians?

Government and health care leaders need to make the values behind their decisions public. They should discuss the values with people who could be affected, ranging from health care workers, who will find themselves on the front lines, to government officials, who are making decisions about the allocation of limited resources, to the public at large, because people will be affected in many ways. They need to do this in advance of a health crisis, not when people are lining up at emergency ward doors.

Openly discussing the choices and confirming that they are based on ethical values that are shared by members of a society brings important benefits. If ethics are clearly built into pandemic plans in an open and transparent manner, and with buy-in from multiple sectors of society, the plans carry greater trust, authority and legitimacy. Advance discussions of such issues can help to address fears of the unknown. People will be more likely to cooperate, and accept difficult decisions made by their leaders for the common good. It is a goal of this paper to provide guidance and to spur a broad public discussion of the often difficult ethical issues underlying decisions.

This fall the World Health Organization (WHO) issued a checklist for influenza pandemic preparedness planning, calling on planners to deal with ethical issues, and to use an ethical framework. The WHO said a framework might deal with such issues as quarantines, the allocation of scarce resources and compulsory vaccinations. The Province of Ontario in Canada built a significant ethics

component into its *Ontario Health Plan for an Influenza Pandemic* of June 2005. The Toronto Academic Health Science Network, made up of all the teaching hospitals in Toronto, is working on a collaborative pandemic plan that will include references to using an ethical framework. Although the JCB Working Group is aware of ethics sections in other plans, we are unaware of any that address the ethical issues in a clear and comprehensive fashion and that articulate the underlying principles and values.

The need for a clearly understood and widely accepted ethics approach to dealing with serious communicable disease outbreaks was underscored during the outbreak of Severe Acute Respiratory Syndrome (SARS) in early 2003. SARS showed the universal vulnerability of humans to communicable diseases, and the need for coordinated and cooperative responses across national borders. It also found that health care systems had generally not prepared themselves to deal with the hard ethical choices that rapidly arose.

Immediately after that outbreak, the JCB produced the report *Ethics and SARS: Learning Lessons from the Toronto Experience*. Since then the JCB has conducted much more detailed research, which is summarized in this paper, and will be published in more detail in separate papers.

Research found that as the SARS crisis became more severe, and restrictions were imposed, there were concerns over access to care and the allocation of medicines, access to safety equipment, who had to work and under what protections, and the sharing of vital information. People started raising the issues of whose values should prevail during a public health emergency.

Leaders in governments and health care systems had not previously developed an ethical framework or held prior consultations on to deal with the suite of ethical issues forced on them by SARS. Decision makers had to balance individual freedoms against the common good, fear for personal safety against the duty to treat the sick, and economic losses against the need to contain the spread of a deadly disease. Decisions had to be rapid, and were as transparent as possible given the limitations of the time. Therefore the lesson learned is to establish the ethical framework in advance, and to do it in a transparent manner.

One major finding of the JCB research was that people are more likely to accept such decisions if the decision-making processes are reasonable, open and transparent, inclusive, responsive and accountable, and if reciprocal obligations are respected. Although these principles can sometimes be difficult to implement during a crisis, SARS showed there are costs from not having an agreed-upon ethical framework, including loss of trust, low morale, fear and misinformation. SARS taught the world that if ethical frameworks had been more widely used to guide decision-making, this would have increased trust and solidarity within and between health care organizations.

SARS gave the world an advance warning of the need for ethical frameworks for decision-making during other communicable disease outbreaks, such as a flu pandemic. JCB research has identified critical issues and ethical principles that can be applied to pandemic planning. The Working Group recommends using these principles to develop a preventive ethics approach. This will have many benefits, including the reduction of conflicts during a crisis.

While much of the research was done in Canada, the lessons are generally applicable around the world. They should be part of the democratic process of making decisions that affect a society.

Following is a comprehensive ethical guide for planning for and dealing with major communicable disease outbreaks, such as pandemic influenza. The guide was developed with expertise from clinical, organizational and public health ethics, and validated through a stakeholder engagement process. It includes both substantive and procedural elements for ethical pandemic influenza planning. This can form the basis for applying the framework that the WHO has recommended. It can be a key planning tool for pandemic readiness.

Next comes a section exploring four key ethical issues that will arise during a flu pandemic. Drawing from the ethical framework, the group identified the applicable key ethical values for each issue, and provides recommendations for dealing with each. The recommendations are particularly addressed to governments and decision-making bodies, mainly in the health care sector, around the world. The key issues are:

1. health workers’ duty to provide care during a communicable disease outbreak;

2. restricting liberty in the interest of public health by measures such as quarantine;

3. priority setting, including the allocation of scarce resources, such as vaccines and antiviral medicines; and

4. global governance implications, such as travel advisories.

These may not be the only ethical issues that the world will face in an influenza pandemic, but they are critically important issues that the Working Group has identified. Planners and decision-makers need to be vigilant for other ethical challenges that will need to be managed.

B. AN ETHICAL GUIDE FOR PANDEMIC PLANNING

Based on the SARS experience, the JCB Working Group has assembled an ethical guide for planning and decision-making that can be used both in advance of and during an influenza pandemic. This guide is composed of 15 ethical values, of which 10 are substantive values and five are procedural values. They should be seen as a package of interdependent values that are important in any democratic society.

B1. Ten substantive values to guide ethical decision-making for a pandemic influenza outbreak

Substantive value	Description
Individual liberty	In a public health crisis, restrictions to individual liberty may be necessary to protect the public from serious harm. Restrictions to individual liberty should: • be proportional, necessary, and relevant; • employ the least restrictive means; and • be applied equitably.
Protection of the public from harm	To protect the public from harm, health care organizations and public health authorities may be required to take actions that impinge on individual liberty. Decision makers should: • weigh the imperative for compliance; • provide reasons for public health measures to encourage compliance; and • establish mechanisms to review decisions.
Proportionality	Proportionality requires that restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is necessary to address the actual level of risk to or critical needs of the community.
Privacy	Individuals have a right to privacy in health care. In a public health crisis, it may be necessary to override this right to protect the public from serious harm.
Duty to provide	Inherent to all codes of ethics for health care professionals is the duty to provide care and to respond to suffering. Health care

care	providers will have to weigh demands of their professional roles against other competing obligations to their own health, and to family and friends. Moreover, health care workers will face significant challenges related to resource allocation, scope of practice, professional liability, and workplace conditions.
Reciprocity	Reciprocity requires that society support those who face a disproportionate burden in protecting the public good, and take steps to minimize burdens as much as possible. Measures to protect the public good are likely to impose a disproportionate burden on health care workers, patients, and their families.
Equity	All patients have an equal claim to receive the health care they need under normal conditions. During a pandemic, difficult decisions will need to be made about which health services to maintain and which to defer. Depending on the severity of the health crisis, this could curtail not only elective surgeries, but could also limit the provision of emergency or necessary services.
Trust	Trust is an essential component of the relationships among clinicians and patients, staff and their organizations, the public and health care providers or organizations, and among organizations within a health system. Decision makers will be confronted with the challenge of maintaining stakeholder trust while simultaneously implementing various control measures during an evolving health crisis. Trust is enhanced by upholding such process values as transparency.
Solidarity	As the world learned from SARS, a pandemic influenza outbreak, will require a new vision of global solidarity and a vision of solidarity among nations. A pandemic can challenge conventional ideas of national sovereignty, security or territoriality. It also requires solidarity within and among health care institutions. It calls for collaborative approaches that set aside traditional values of self-interest or territoriality among health care professionals, services, or institutions.
Stewardship	Those entrusted with governance roles should be guided by the notion of stewardship. Inherent in stewardship are the notions of trust, ethical behaviour, and good decision-making. This implies that decisions regarding resources are intended to achieve the best patient health and public health outcomes given the unique circumstances of the influenza crisis.

B2. Five procedural values to guide ethical decision-making for a pandemic influenza outbreak

Procedural value	Description
Reasonable	Decisions should be based on reasons (i.e., evidence, principles, and values) that stakeholders can agree are relevant to meeting health needs in a pandemic influenza crisis. The decisions should be made by people who are credible and accountable.
Open and transparent	The process by which decisions are made must be open to scrutiny, and the basis upon which decisions are made should be publicly accessible.
Inclusive	Decisions should be made explicitly with stakeholder views in mind, and there should be opportunities to engage stakeholders in the decision-making process.
Responsive	There should be opportunities to revisit and revise decisions as new information emerges throughout the crisis. There should be mechanisms to address disputes and complaints.
Accountable	There should be mechanisms in place to ensure that decision makers are answerable for their actions and inactions. Defence of actions and inactions should be grounded in the 14 other ethical values proposed above.

Recommendations

1. National, provincial/state/territorial, and municipal governments, as well as the health care sector, should ensure that their pandemic plans include an ethical component.

2. National, provincial/state/territorial, and municipal governments, as well as the health care sector, should consider incorporating both substantive and procedural values in the ethical component of their pandemic plans.

C. FOUR KEY ETHICAL ISSUES

As a result of analyses of the SARS crisis, the JCB Working Group identified four key ethical issues that are expected to be very important during a pandemic flu outbreak. Below, each of these issues is described in turn to illustrate how this ethical guide can be used. Specific recommendations are included for each issue.

C1. Health workers' duty to provide care during a communicable disease outbreak

During SARS, some medical workers were afraid that they would be infected while caring for SARS patients, and that they would infect their families, friends and co-workers. The workers were torn between these fears and a sense of duty to their patients and solidarity with fellow workers. A flu pandemic will mean virtually all health care workers will face such difficult choices.

Overview

The duty to care for the sick is a primary ethical obligation for health care workers for a number of reasons, including:

1. the ability of physicians and health care workers to provide care is greater than that of the public, thus increasing their obligation to provide care.
2. by freely choosing a profession devoted to care for the ill, they assume risks.
3. the profession has a social contract that calls on members to be available in times of emergency. (In addition, they largely work in publicly supported systems in many countries.)

When SARS broke out, health care workers in a number of countries were on the firing line, and had to make decisions for which they were not always prepared. They faced an unknown and deadly communicable disease, a coronavirus for which there was no known effective treatment. They were rapidly forced to weigh serious and imminent health risks to themselves and their families against their duty to care for the sick. A significant number of health care workers were infected with SARS because of their work, and some died. Many workers were placed under work quarantine.

Workers generally showed heroism and altruism in the face of danger during the SARS outbreak, but some balked at caring for people infected with SARS, and a few were dismissed for failing to report for duty. Post-SARS, many health care workers raised concerns about the level of protection to themselves and their families. Some even left the profession.

A flu pandemic would put far greater pressures on health care systems around the world. Faced with a very serious disease for which there may be no absolute protection or cure, health care workers will find themselves facing overwhelming demands. They will be forced to weigh their duty to provide care against competing obligations, such as their duty to protect their own health and that of families and friends. Initially the primary care and emergency services workers will take the full brunt of responding to the flu, and therefore bear a disproportionate risk compared to more specialized care providers. There will likely be pressure on other health care providers to come to the front lines.

Some believe that under dire circumstances, professionals should have minimal self-regard and pursue their duties at potential cost to their own lives. By analogy, firefighters do not have the freedom to choose whether or not they have to face a particularly bad fire, and police do not get to select which dark alleys they walk down. Others claim that it is unreasonable to demand extreme heroism from health care workers as the norm, and even more unreasonable to demand that workers put the lives of their families at high risk or make themselves unavailable to care for them should they become ill.

At times like this, health care workers' ethical codes should provide important guidance on such issues as professional rights and responsibilities. It is important for health care professionals, from doctors to nurses to hospital and ambulance staff, to articulate codes or statements of ethical conduct in high-risk situations, so that everyone knows what to expect during times of communicable disease crises. These codes or statements should cover such issues as:

- how much risk should health care workers be required to take;
- their duty to care for the sick, and to care for themselves so they can continue to provide care; and
- their duty not to harm others by transmitting diseases.

There is currently a vacuum in this field. For example, the 2004 Canadian Medical Association (CMA) revised *Code of Ethics*, released a year after SARS, provides no clear guidance on the key ethical issues raised by communicable disease outbreaks, including the duty to care. The JCB Working Group has looked at a number of medical codes of ethics in other countries and found a similar lack of specific guidance on these issues.

In the past, particularly after the 1919 influenza pandemic, such issues were explicitly addressed by some codes. For example, the 1922 *CMA Code of Ethics* said: “When pestilence prevails, it is their (physicians') duty to face the danger, and to continue their labours for the alleviation of suffering, even at the jeopardy of their own lives.” The American Medical Association used similar language in its code of ethics from 1846 until the 1950s. The disappearance of this stringent demand from medical codes of ethics is unexplained, perhaps related to belief in recent decades that dangerous communicable diseases had been vanquished. The resurgence of communicable diseases for which there are no ready defences raises the need for clarity from the professions.

While much of the discussion post SARS has been about the duties of health care workers, there are other important ethical issues that need to be addressed, including reciprocity and solidarity. If workers are to take high risks, there is a duty upon society, in particular on their institutions, to support them. The institutions need to plan to help workers cope with the high stress of a pandemic, to acknowledge that their work is dangerous. For example, they need to provide for the health and safety of workers, and for the care of those who fall ill on duty. This might include an insurance fund for life and disability to cover health care workers who become sick or die as they place themselves in harm’s way. Also, there is a need for fair and workable human resource plans for emergency situations. Limitations imposed during SARS resulted in a loss of work for some health care workers. The imposition of employment restrictions should not result in financial hardship or job loss and should not unduly affect part-time staff.

The risk to care providers is not only physical, but also psychological. Senior decision makers and physicians will have to make many hard choices about care and the assignment of staff. They need to feel that they have the support of the highest levels of administration, including boards of directors.

Just after the SARS crisis, a JCB paper recommended a review of professional codes to help clarify professional duties and define the acceptable extent of professional obligation. That paper recommended that health care institutions develop ethical frameworks in collaboration with their workforce, establish explicit work expectations in times of communicable disease, and make them available to their staffs.

Ethical values and processes

Based on the guide of substantive values and process for ethical decision-making, the substantive values most applicable to this issue are: duty to provide care, reciprocity, trust, and solidarity.

All five procedural values apply: reasonable, open and transparent, inclusive, responsive, and accountable.

Recommendations

1. Professional colleges and associations should provide, by way of their codes of ethics, clear guidance to members in advance of a major communicable disease outbreak, such as pandemic flu. Existing mechanisms should be identified, or means should be developed, to inform college members as to expectations and obligations regarding the duty to provide care during a communicable disease outbreak.

2. Governments and the health care sector should ensure that:

    a. care providers' safety is protected at all times, and providers are able to discharge duties and receive sufficient support throughout a period of extraordinary demands; and

    b. disability insurance and death benefits are available to staff and their families adversely affected while performing their duties.

3. Governments and the health care sector should develop human resource strategies for communicable disease outbreaks that cover the diverse occupational roles, that are transparent in how individuals are assigned to roles in the management of an outbreak, and that are equitable with respect to the distribution of risk among individuals and occupational categories.

C2. Restricting liberty in the interest of public health by measures such as quarantine

During the SARS outbreak, a number of people, including health care staff, were ordered to remain at home to prevent spreading the disease. People faced the loss of income and possibly their jobs. The number of people affected could be far higher during a global flu pandemic, and people subject to restrictive measures will need to have their basic needs met, including some protection for their income and jobs.

Overview

Until a new flu vaccine is developed or other medications are found to control pandemic flu, restrictive measures may be one of the important public health tools to reduce spread of this communicable disease. Governments may need to limit three basic personal freedoms that we take from granted: mobility, freedom of assembly and privacy. They may close schools, cancel public gatherings and

sporting events, and impose quarantine, isolation and even detention, where needed.

During SARS, a significant number of people were placed in quarantine to control the spread of this disease, making it one of the largest quarantines in modern times. A major flu pandemic could result in very large numbers being subjected to such measures. These restrictions impose a heavy burden on those affected. People may be cut off from family, friends, work, shopping, entertainment, travel, and most other activities, including some forms of medical care. People may feel stigmatized if they are put into quarantine or identified as being affected by pandemic flu.

JCB research in the aftermath of SARS showed that people understood and accepted the need for restrictive measures for the control of communicable diseases. Most saw it as a form of civic duty, and were willing to make a sacrifice. However, our data also indicate that if decision makers expect full compliance with restrictive measures, the decisions need to be made in a fair manner, and people affected by such measures need support. Reciprocity requires society in turn to ensure that those affected receive adequate care, and do not suffer unfair economic penalties. If leaders expect people exposed to or suffering from communicable diseases to act in a manner that does not put others at risk, it is important that they create a social environment that does not leave people without supports.

For example, if quarantine is implemented, governments should ensure that people have adequate food supplies and are able to carry out essential functions. Their jobs should be protected, and they should not suffer an undue financial burden. Volunteer organizations will have a vital role to play, but since they are voluntary, they do not have the same ethical obligations as governments.

There will be related issues, including the privacy of personal information and the public needs to know about high risks of disease. In SARS, the outbreak in Canada was linked to a traveller from China, leading to some people boycotting Chinese businesses elsewhere.

The state has the right to override an individual’s right to privacy in cases of serious public health risks if revealing private medical information helps to protect public health. Governments also have an obligation to reduce stigmatization by respecting the value of privacy as much as possible, and by providing accurate information, and only the information that will give the public a realistic view of such key public health issues as the spreading of disease.

The world could face the possibility of other measures that could be used to contain the disease, including mandatory vaccination, surveillance cameras, monitoring devices, and even imprisonment for people who failed to comply with quarantine orders.

Restrictive measures are a reminder of the legitimate limits to our highly prized individual liberties. When making such decisions, leaders will need to balance individual freedoms against the common good of society, fear for personal safety against the duty to treat the sick, and economic losses against the need to contain the spread of a deadly disease. Authorities exercising public health powers should do so in a way that is relevant, legitimate, legal, proportional, and necessary. They should use the least restrictive methods that are reasonably available to limit individual liberties, and should apply restrictions without discrimination. People need to be fully informed about issues, including risks and benefits of public health measures.

Decision makers need to turn for guidance to documents such as charters of rights and freedoms and human rights legislation. They can look to the United Nations' Siracusa Principles, which are based upon human rights documents. The principles stipulate the extent to which state powers should be exercised in times of public health emergencies. The principles hold that public health may be invoked as grounds for limiting certain rights in order to manage a serious threat to the health of individuals or a population. These measures must be specifically aimed at preventing disease or injury, or providing care for the sick and injured. The actions taken must be legal, necessary, and proportional to the threat.

In November 2005, the American Medical Association issued guidelines for protecting patient rights if they have to be quarantined during an epidemic. An AMA spokesperson said: "…Physicians must do everything they can to protect the rights and privacy of patients without compromising the health of the public."

Ethical values and processes

Based on our guide of substantive values and process for ethical decision-making, the substantive values most applicable to this issue are: liberty, protection of public from harm, proportionality, privacy, and reciprocity.

All five procedural values apply: reasonable, open and transparent, inclusive, responsive, and accountable.

Recommendations

1. Governments and the health care sector should ensure that pandemic influenza response plans include a comprehensive and transparent protocol for the implementation of restrictive measures. The protocol should be founded upon the principles of proportionality and least restrictive means, should balance individual liberties with protection of public from harm, and should build in safeguards such as the right of appeal.

2. Governments and the health care sector should ensure that the public is aware of:

    a. the rationale for restrictive measures;
    b. the benefits of compliance; and
    c. the consequences of non-compliance.

3. Governments and the health care sector should include measures in their pandemic influenza preparedness plans to protect against stigmatization and to safeguard the privacy of individuals and/or communities affected by quarantine or other restrictive measures.

4. Governments and the health care sector should institute measures and processes to guarantee provisions and support services to individuals and/or communities affected by restrictive measures, such as quarantine orders, implemented during a pandemic influenza emergency. Plans should state in advance what backup support will be available to help those who are quarantined (e.g., who will do their shopping, pay the bills, and provide financial support in lieu of lost income). Governments should have public discussions of appropriate levels of compensation in advance, including who is responsible for compensation.

C3. Priority setting, including the allocation of scarce resources, such as vaccines and antiviral medicines

One of the side effects of SARS was that people scheduled for important treatments, such as cancer surgery, had their care postponed. A number of hospital beds, staff and equipment were redirected to the public health emergency. These kinds of decisions will be even more prevalent during a flu pandemic.

Overview

If the flu pandemic is as severe as some fear, there will be an extraordinarily high number of sick people around the world, all requiring care at the same time. This will be on top of the "normal" health care needs, which strain medical systems at the best of times. During a pandemic, the human and material resources of health care will be rapidly overwhelmed. There will be scarcities of medicines, equipment and health care workers in all countries, with less-developed nations facing some of the greatest scarcities. There will be cases of people who will have to forego medical care for other ailments, such as cancer and heart disease.

Decision makers will seek to maximize benefits for society while balancing obligations to individuals and individual needs. They will have to decide who gets access to vaccines, antiviral drugs, such as Tamiflu, ventilators, and other forms of care. They will use priority-setting processes, also known as rationing or resource allocation. This means that current societal expectations about access to health care will have to change in light of a public health crisis of major proportions.

Already there are signs of a public debate over choices. Some jurisdictions are stockpiling Tamiflu rather than allowing unlimited private sales. Most pandemic plans give priority for the use of antivirals and vaccines to health care workers and people in emergency services. Some plans state that once a vaccine is developed, children would be among the last to be immunized. This is based on experience with flu in the past, showing that after age 2, children are most likely to survive the virus. While these choices are justifiable, it would help to build public support by discussing them in a public manner.

People expect decisions to be reasonable, open and transparent, inclusive, responsive, and accountable. In the midst of a pandemic, when guidance will be incomplete, consequences uncertain, and information constantly changing, and where hour-by-hour decisions involve life and death, fairness is crucial. Experience shows that there is often disagreement on what principles should be used to make fair allocation decisions. This means that decision makers may have also to rely on a fair process to establish the legitimacy of priority setting decisions.

There is still time for many decisions to be made in consultation with stakeholders and the public. Although the organizational leaders would ultimately be accountable for making the priority setting decisions, a broader range of stakeholders should be engaged particularly as key informants through expert and broader stakeholder consultation. The stakeholders can range from employees and patient groups to institutional partners, community groups, and government officials.

People need to know in advance what to expect. An effective communications strategy should be developed to ensure a transparent priority setting process. The purpose of the communication strategy should be to ensure that stakeholders know and understand the scope and necessity of priority setting decision-making, the degrees of freedom within which priority setting would take place and the roles of various people. In addition, the rationales for priority setting decisions should be communicated to stakeholders, and should clearly demonstrate how these decisions are defensible in light of the priority setting criteria and available data and information.

Among the benefits of open communications about priority-setting:

- stakeholders feel engaged and understand the decision-making process;

- priorities can be justified and seen to be reasonable; and
- the process is perceived to be fair.

Ethical values and processes

Based on our guide of substantive values and process for ethical decision-making, the substantive values most applicable to this issue are: equity, trust, solidarity, and stewardship.

All five procedural values apply: reasonable, open and transparent, inclusive, responsive, and accountable.

Recommendations

1. Governments and the health care sector should publicize a clear rationale for giving priority access to health care services, including antivirals and vaccines, to particular groups, such as front line health workers and those in emergency services. The decision makers should initiate and facilitate constructive public discussion about these choices.

2. Governments and the health care sector should engage stakeholders (including staff, the public, and other partners) in determining what criteria should be used to make resource allocation decisions (e.g., access to ventilators during the crisis, and access to health services for other illnesses), should ensure that clear rationales for allocation decisions are publicly accessible and should provide a justification for any deviation from the pre-determined criteria.

3. Governments and the health care sector should ensure that there are formal mechanisms in place for stakeholders to bring forward new information, to appeal or raise concerns about particular allocation decisions, and to resolve disputes.

C4. Global governance implications, such as travel advisories

In rural China, a farmer developed a chest infection, and then family travels began a chain of events that would take the SARS virus to the other side of the world. In Geneva, officials of the World Health Organization (WHO) weighed the risk of the spread of SARS, and issued travel warnings that would affect a number of countries, sometimes causing severe economic impacts.

The current avian flu virus is moving across vast distances, carried by wild birds.

If this virus mutates to become transmissible among humans, the WHO has warned that it could reach all continents in less than three months. The WHO will have to carefully consider when it will institute travel measures to protect the global community from spread of the disease.

Overview

The SARS outbreak showed our global interdependence, and the increasing risk to global human security from the emergence and rapid spread of communicable diseases. It showed the need for global solidarity, involving highly coordinated public health responses that involve the cooperation of local, regional, national, and supra-national governments.

One way that governments and the WHO seek to control the spread of communicable diseases is through restrictions on travel. Especially during the early stages of what looks like a pandemic, travel advisories can help to slow the spread of the virus. These restrictions can impose severe penalties not only on individuals, but also on entire regions. The ethical challenges of global public health decision-making are well illustrated by the issuance of travel advisories.

During the 2003 SARS crisis, the WHO advised international travelers against all non-essential travel to a number of regions, including parts of China, including Hong Kong, as well as Taiwan and Toronto. There were many side effects of those public health decisions. The reduction in travel and tourism cost Canada, particularly Toronto and the province of Ontario, many millions of dollars in economic losses.

Analysis of the SARS case showed that federal states, where powers are shared among national and provincial or state governments, can face problems in organizing themselves to respond to public health crises. During SARS, the Canadian federal government's ability to obtain data from the Province of Ontario was dependent on voluntary transfer since the management of communicable disease outbreaks falls under provincial jurisdiction. Problems with communication among governments may have led to a delay in providing information on SARS to the WHO. This in turn could have undermined the WHO's confidence in the Canadian response, which perhaps contributed to the imposition of the travel advisory on Toronto.

While it was the duty of the WHO to do everything it could to prevent the spread of SARS to other countries, and in particular developing countries that have limited resources to combat the spread of the disease, it had to do so in a manner that was respectful of national sovereignty. Conversely, nations such as Canada had a responsibility as members of the global community to cooperate fully in the international pandemic response.

The Working Group's examination of global governance has centered on the issue of travel advisories as well as national and international responsibilities related to pandemic response. In particular, any decision by the WHO that can infringe upon the sovereignty of a nation needs to be clearly justified and the process must be transparent. There were concerns about the issuance of travel advisories during SARS. These issues have been addressed in the revised International Health Regulations (IHR), which have formalized the process by which the WHO can take such measures. The WHO must carefully consider how and when it issues travel recommendations. The issuing of recommendations that are perceived by nations to be inappropriate could lead to their lack of confidence in the WHO's leadership, and also undermine their support for the IHR. Conversely, the failure of the WHO to institute travel advisories in a timely manner, perhaps due to political pressure, could lead to the otherwise preventable spread of the pandemic.

Individual countries have a responsibility to the international community to communicate information on the emergency of public health threats. The revised international health regulations have outlined these responsibilities primarily as they relate to surveillance. However, countries with federal systems of government may not be able to comply with these responsibilities due to the allocation of powers within the country. This is potentially true for such countries as Canada, the United States, and Australia. Ultimately, it is the responsibility of these countries to utilize whatever policy instruments the federal governments have available to ensure that they can comply with the requirements of the new IHR.

The surveillance responsibilities of individual countries may be beyond the capacity of many developing countries. These countries are being pressured to improve their existing surveillance infrastructure. However, doing so may divert resources from areas in which needs are much greater in order to achieve goals that are more in the interest of developed countries. Developed countries must be aware of this trade-off and take measures, most suitably in the form of increased investment, to ensure that enhanced surveillance does not occur at the expense of managing the multitude of ongoing public health threats many developing countries face.

To sum up, protecting global health requires governments around the world to show solidarity and to be open and transparent in the way they carry out health protection responsibilities.

Ethical values and processes

Based on our guide of substantive values and process for ethical decision-making, the substantive values most applicable to this issue are: protection of the public from harm, proportionality, trust, and solidarity.

All five procedural values apply: reasonable, open and transparent, inclusive, responsive, and accountable.

Recommendations

1. The World Health Organization should remain aware of the impact of travel recommendations on affected countries, and should make every effort to be as transparent and equitable as possible when issuing such recommendations.
2. Federal countries should utilize whatever mechanisms are available within their system of government to ensure that relationships within the country are adequate to ensure compliance with the new International Health Regulations.
3. The developed world should continue to invest in the surveillance capacity of developing countries, and should also make investments to further improve the overall public health infrastructure of developing countries.

C5. Other ethical issues

In addition to the four key ethical issues explored by the JCB Working Group, there may be other important issues that people feel should be discussed in advance of a pandemic. These might include, for example:

- research ethics during a public health emergency;
- the ethical treatment of animals, such as the culling of poultry flocks, during a public health emergency; and
- compensation for farmers put out of business and loss of food supply and income resulting from mass culls.

This paper should be seen as fostering a public debate and providing guidance on issues that have been carefully studied.

D. NEXT STEPS

The JCB Working Group strongly encourages all governments and health care systems around the world to assess their pandemic plan against the ethical framework and recommendations presented in this discussion paper.

Looking ahead, we can say that if the pandemic strikes it will cause great hardship, but societies will struggle through. They will be better able to do so if they have prepared in all possible ways, including having general agreement on an ethical approach. Afterwards, history will judge today's leaders on how well they prepared for and acted during the crisis and if they treated people in an ethical manner.

The Working Group looks forward to receiving comments on this discussion paper, and encourages an open dialogue on its key points and recommendations.

E. END MATERIALS

Consolidated list of recommendations:

An ethical guide for pandemic planning

1. National, provincial/state/territorial, and municipal governments, as well as the health care sector, should ensure that their pandemic plans include an ethical component.

2. National, provincial/state/territorial, and municipal governments, as well as the health care sector, should consider incorporating both substantive and procedural values in the ethical component of their pandemic plans.

Recommendations from Issue 1

Health workers' duty to provide care during a communicable disease outbreak

1. Professional colleges and associations should provide, by way of their codes of ethics, clear guidance to members in advance of a major communicable disease outbreak, such as pandemic flu. Existing mechanisms should be identified, or means should be developed, to inform college members as to expectations and obligations regarding the duty to provide care during a communicable disease outbreak.

2. Governments and the health care sector should ensure that:

    a. care providers' safety is protected at all times, and providers are able to discharge duties and receive sufficient support throughout a period of extraordinary demands; and

b. disability insurance and death benefits are available to staff and their families adversely affected while performing their duties.

3. Governments, hospitals and health regions should develop human resource strategies for communicable disease outbreaks that cover the diverse occupational roles, that are transparent in how individuals are assigned to roles in the management of an outbreak, and that are equitable with respect to the distribution of risk among individuals and occupational categories.

Recommendations from Issue 2

Restricting liberty in the interest of public health by measures such as quarantine

1. Governments and the health care sector should ensure that pandemic influenza response plans include a comprehensive and transparent protocol for the implementation of restrictive measures. The protocol should be founded upon the principles of proportionality and least restrictive means, should balance individual liberties with protection of public from harm and should build in safeguards such as the right of appeal.

2. Governments and the health care sector should ensure that the public is aware of:

    a. the rationale for restrictive measures;
    b. the benefits of compliance; and
    c. the consequences of non-compliance.

3. Governments and the health care sector should include measures in their pandemic influenza preparedness plans to protect against stigmatization and to safeguard the privacy of individuals and/or communities affected by quarantine or other restrictive measures.

4. Governments and the health care sector should institute measures and processes to guarantee provisions and support services to individuals and/or communities affected by restrictive measures, such as quarantine orders, implemented during a pandemic influenza emergency. Plans should state in advance what backup support will be available to help those who are quarantined (e.g., who will do their shopping, pay the bills and provide financial support in lieu of lost income). Governments should have public discussions of appropriate levels of compensation in advance, including who is responsible for compensation.

Recommendations from Issue 3

Priority setting, including the allocation of scarce resources, such as vaccines and antiviral medicines

1. Governments and the health care sector should publicize a clear rationale for giving priority access to health care services, including antivirals and vaccines, to particular groups, such as front line health workers and those in emergency services. The decision makers should initiate and facilitate constructive public discussion about these choices.

2. Governments and the health care sector should engage stakeholders (including staff, the public and partners) in determining what criteria should be used to make resource allocation decisions (e.g., access to ventilators during the crisis, and access to health services for other illnesses), should ensure that clear rationales for allocation decisions are publicly accessible and should provide a justification for any deviation from the pre-determined criteria.

3. Governments and the health care sector should ensure that there are formal mechanisms in place for stakeholders to bring forward new information, to appeal or raise concerns about particular allocation decisions and to resolve disputes.

Recommendations from Issue 4

Global governance implications, such as travel advisories

1. The World Health Organization should remain aware of the impact of travel recommendations on affected countries, and should make every effort to be as transparent and equitable as possible when issuing such recommendations.

2. Federal countries should utilize whatever mechanisms are available within their system of government to ensure that relationships within the country are adequate to ensure compliance with the new International Health Regulations.

3. The developed world should continue to invest in the surveillance capacity of developing countries, and should also make investments to further improve the overall public health infrastructure of developing countries.

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