

Health Ethics Considerations: Planning for and Responding to Pandemic Influenza in Missouri

Background and Scope

Public health emergency preparedness and response is a vital health function that is both a governmental responsibility and a civic endeavor. To be effective, it requires a capacity for assessing health risk, legal authority, worked-out roles and responsibilities, incident command, public engagement, capable epidemiology, laboratory capacity, countermeasure and mitigation strategies, provision of mass healthcare, robust supply chains, and a trained and staffed workforce.

This document presents an ethical framework to guide pandemic influenza planning and response in Missouri. It was developed by a statewide consortium of health ethics organizations convened by the Center for Health Ethics at the University of Missouri School of Medicine acting on a request by, and with funding from, the Missouri Department of Health and Senior Services.

The Consortium gratefully acknowledges its debt to the Centers for Disease Control and Prevention (CDC) and the consultation of other national and international resources.

We recommend that this paper be disseminated widely and vetted in local communities across Missouri, that is, that it be further developed and validated through a stakeholder engagement process involving the public, healthcare professionals and institutions, and other civic and private institutions. We believe that successful planning relies on and taps into preexisting traditions of civic responsibility, justice, and concern for others. But emergency planning can and should also be an occasion to foster these outlooks and impulses. Fear and self-interest may be evident during an influenza pandemic. But public health leadership can move communities beyond those motivations to a sense of common purpose and solidarity.

In drafting this document, the Consortium recognizes the need for decision makers at all levels to transform this ethical framework into specific guidelines. Ethical decision making assumes that specific guidelines will be developed locally based on good medical practice (i.e., accepted standards of care), scientific knowledge, cultural norms, and community participation so that the effectiveness of interventions can be carefully assessed. As each community considers how best to use this ethical framework, decision makers will identify which ethical issues need to be addressed, how best to use this ethical framework, and what specific guidelines are needed to prepare for and respond to pandemic influenza. They will also develop processes for assessing how their decisions affect the community and how the guidelines can be adapted to fit changing conditions during the pandemic event. Most important, they will also develop processes for ensuring the transparency of their decisions, for evaluating the effectiveness of the guidelines, and for sharing their experience with others.

1. Purpose / Rationale / Goals

The purpose of this document is to assist Missouri's citizens, organizations, and public health decision makers in balancing their responsibility to preserve the functioning of society across communities in times of pandemic influenza with protecting to the greatest extent possible the

personal freedom and individual liberties of every citizen. Specific goals are to

- inform Missouri decision makers concerning health ethics considerations that affect their plans for responding to pandemic influenza, and
- establish a framework for pandemic influenza planning and response that articulates and promotes our most commonly accepted values.

The seven values that the CDC characterizes as most pertinent to public health emergency planning and response are

- harm reduction and benefit promotion,
- equal liberty and human rights,
- distributive justice,
- public accountability and transparency,
- community strength and resiliency,
- public health professionalism, and
- civic and personal responsibility.

Respect for individual liberty, incontestably among the values most widely accepted in democratic societies, is certainly a bedrock value in Missouri. But membership in society is conditioned on acceptance of constraints on individual liberty when the exercise of that liberty places other citizens at risk. Pandemic influenza carries a high risk that exercising individual liberties may harm other citizens. The Consortium recognizes, therefore, that placing societal constraints on individual liberties is justifiable in the context of a public health emergency. Nevertheless, we know from both history and common sense that constraints on liberty should be publicly justified, show respect for the privacy and confidentiality of those constrained and protect them against social stigma and humiliation.

The Consortium adopted a public health perspective to guide its deliberations. The practice of medicine is patient centered—its goal is to promote individual health. The goal of pandemic influenza preparedness and response is to help ameliorate the consequences of widespread disease. The Consortium recognizes the parity of these goals and their complementarity. Protecting the community's health becomes the overarching goal during a public health emergency because it is the most effective way in such circumstances to reduce individual morbidity and mortality, that is, to promote individual health.

The Consortium also notes that healthcare issues (e.g., issues concerning clinical decision making, standards of care, and the structures of healthcare delivery) are central to pandemic influenza preparedness and response. However, these clinical ethical issues are beyond the scope of this document. The Consortium plans to address these and similar issues that healthcare providers and their organizations will face during pandemic influenza in a separate, linked document.

2. Working Assumptions

In addition to adopting a public health perspective, the Consortium made several assumptions.

- Missouri will maintain its all-hazards approach to public health emergency preparedness and adapt it to the particular requirements of pandemic influenza preparedness.
- Pandemic influenza preparedness will include involving, educating, and supporting

citizens and communities.

- Public health decision-making processes related to pandemic influenza will be transparent and linked to communities.
- The use of governmental power and authority to implement pandemic influenza response plans will be subject to ongoing monitoring.
- As individual, community, and regional needs and capabilities differ, the guidelines developed at each level will naturally vary.
- To gauge effectiveness, learn from mistakes, and improve future responses, ongoing and after-the-fact evaluations and assessments will be integral to pandemic influenza plans and responses.

3. Working Definitions

Epidemic/pandemic – An epidemic is the occurrence in a community or a region of cases of an illness, specific health-related behavior or other health-related events clearly in excess of normal expectancy. A pandemic is an epidemic occurring worldwide or over a wide area crossing international boundaries, and affecting a large number of people.

Mitigation activity – Any undertaking intended to minimize harm or restore lost capacity and strength to communities affected by a public health emergency. Implementing a pandemic influenza response plan is a mitigation activity.

Public health emergency – A public health emergency exists whenever a situation arises that may overwhelm the routine capabilities for protecting the public's health. Pandemic influenza is such an emergency.

Public health emergency preparedness and response – The capability of the public health and healthcare systems, communities, and citizens to prevent, protect against, quickly respond to, and recover from health emergencies, particularly when the scale, timing, or unpredictability of the emergency threatens to overwhelm routine capabilities.

Vulnerable populations – Persons or groups having special susceptibility to harm and injustice during a public health emergency. Vulnerability is often described in terms of individual or group traits, for example, health status, capability, and personality. Vulnerability may also be understood as a function of the social systems and resources that limit the options and impair the ability of persons or groups to receive services or protect themselves in the face of danger.

4. Conceptual Framework

The conceptual framework for this guidance document is a set of ethical goals and a related set of ethically informed decision-making processes.

Ethical Goals

An array of values and activities define the goals of the planning and response process.

- *Harm reduction and benefit promotion.* Pandemic influenza planning and response should maximize public safety, health, and well-being. Death, injury, disease, disability, and suffering should be minimized.
- *Liberty and human rights.* Planning for and responding to pandemic influenza should be respectful of every citizen's liberty and autonomy.
- *Distributive justice.* The benefits and burdens of pandemic influenza planning and

- response should be equitably shared by all citizens.
- *Public accountability and transparency.* Pandemic influenza planning and response should rely on inclusive, transparent decision-making processes. The rationale for decisions should be articulated, and the values relied on should be identified and open for examination.
 - *Community strength and resiliency.* Public involvement in pandemic influenza planning and response is essential to building public will and trust. Over time pandemic influenza planning and response should develop hazard-resistant, resilient communities that have robust internal support systems, networks of mutual assistance, and solidarity.
 - *Public health professionalism.* Public health professionals have a responsibility to maximize preparedness. The competency of these professionals should be recognized and their efforts coordinated.
 - *Responsible citizenship.* Pandemic influenza planning and response activities should promote personal responsibility and citizenship.

Ethical Decision-making Processes

All decisions, whether they are, for example, primarily administrative, corporate, political, clinical, or ethical, involve choice and embody substantive values. Therefore, it is important that the decision-making process itself should always be guided by procedural values that ensure transparency and build trust. Decisions made in pandemic influenza preparedness and response planning will be ethically appropriate if they share the following traits:

- *Shared goals.* The overall goals of pandemic planning will be clear and consonant with the goals and objectives of the public health profession.
- *Evidence-informed deliberation.* Decisions will reflect the best available evidence; even during an emergency, arbitrary and ill-informed decisions are not acceptable.
- *Considerate, collaborative discussion.* Decision-making processes are both explicit and empathetic – they will put a face on the people and groups who are most directly affected.
- *Responsibility.* Decision makers will be aware of, and accountable for, the ethical dimensions and consequences of their decisions.

5. Principles of Ethics

The nature and complexity of emergency planning and response require ethical analysis at several different levels. Although the same principles/values that apply in everyday circumstances are important during a public health emergency, few communities will have a clear consensus regarding the proper weight that should be attributed when principles/values conflict during a public health emergency. No one conception of justice, for example, such as an emphasis on aggregate well-being and efficiency or an emphasis on equity, can provide the necessary solution to ethical dilemmas in practice. The following paragraphs reflect the kinds of thinking that can inform our more practical efforts to think through the conflicts of value that may be experienced in a public health emergency such as a pandemic influenza.

Justice and Fairness

Planners and policymakers should identify in advance known or potential burdens of response plans and determine upon whom those burdens are likely to fall. They should seek to minimize such burdens by considering alternative approaches. When burdens must be imposed, the

imposition should be as equitable as possible, that is, fair to all concerned and free of prejudice or favoritism.

Policies and decisions should not unduly burden any one segment of the population and should strive for an even-handed and uniform pattern of assistance and recovery. Measures taken in response to emergencies have the effect of distributing risk. The distribution of risk ought to be equitable and seek to balance individual and societal interests. In general, priority in recovery efforts should be provided on the basis of greatest need, for example, those at greatest health risk due to the dislocation of their ordinary routines and modes of living should be given special attention.

Fairness should be a feature not only of the outcome of mitigation activities but also of the way in which they are conducted and carried out. Planners should attempt to make the public health benefits and the accompanying social, economic, and personal burdens balanced and proportionate.

Respecting People with Special Needs or Vulnerabilities

In every community there are people who will be particularly susceptible to harm or injustice during an influenza pandemic. In emergencies, when many persons are in distress, the voices of the vulnerable and those who have been socially or culturally marginalized are most likely to be drowned-out. Therefore, the planning process should include careful identification and assessment of these vulnerable persons or groups and their needs.

Accountability and Transparency

The use of power and authority to implement pandemic influenza response plans should be carefully monitored to ensure that power and authority are not abused and that paternalistic or coercive measures are justified by circumstances. There should be ongoing and post disaster evaluation and assessment of emergency plans and their implementation. The pervasive uncertainty of pandemic influenza requires that conclusions about the fairness of a proposed mitigation activity be considered provisional and subject to revision over time as the pandemic unfolds. Flexibility in responding to changing conditions and evolving knowledge is crucial.

Transparency requires two-way exchanges that provide opportunities for citizens to participate in, reflect on, and rationally accept planning decisions. The traits of transparency include patience, flexibility, acknowledgement of mistakes and uncertainty, timely follow-up, practicable advice, and solidarity with the community.

Respect for Individual Liberties

Respect for the right of citizens to make their own decisions is derived from the sense that an inherent dignity endows human persons with a general right to noninterference. However, responding to pandemic influenza may include interventions that constrain personal freedom or create conditions of social distancing. Compliance with such interventions should not be mandatory unless voluntary compliance proves, or seems likely to prove, ineffective.

Liberty-limiting and social-distancing interventions should be based on the best available evidence. However, the evidence base for such interventions is incomplete, and it may be necessary to mandate interventions for which there is little or no evidence. Therefore, we recommend a standard of “evidence-informed” rather than “evidence-based” decision-making.

Implementing any of the following interventions will constrain personal freedoms:

- isolating citizens infected or ill with influenza;

- quarantining citizens believed to be exposed, including family members and others in close contact;
- closing schools, canceling public events, and closing public venues;
- restricting access to “essential” public venues;
- modifying office and work-scheduling practices; or
- limiting travel.

6. Ethical Considerations Specific to Pandemic Planning and Response

Saving Lives and Preventing Illness

In addition to meeting its primary goal of respecting and promoting human life, safety, and well-being, public health emergency planning and response should minimize psychological harm and trauma, economic loss, and environmental damage. In a pandemic, protecting the public’s health and safety will also reduce individual harm, morbidity, and mortality.

Placing Constraints on Liberty

The processes for making decisions that constrain liberty should be carefully analyzed and a reasonably diverse infrastructure that crosses racial, cultural, and community divides should be established for understanding, planning, and informing stakeholders. A process should also be in place for objections to be heard, restrictions appealed, and for new procedures to be considered prior to implementation.

The public should be clearly informed that constraints are anticipated, necessary to limit the spread of disease throughout the community, and potentially important to protect individual citizens.

Communication should encourage individuals to partner with their communities and society at large in controlling influenza transmission. Information should be provided thoughtfully, balancing the need for disclosure and information with protection of privacy and public trust.

Exercising the power to protect the community by restricting individual freedom requires careful reflection and examination so that respect for personal freedom remains intact. We cannot take lightly the history of neglect and abuse of personal freedom that has occurred in multiple U.S. health programs.

During an influenza pandemic there may be a strong justification for centralized decision making, since general maxims and criteria for restrictions on personal freedom must be supported by equity and the need to preserve the functioning of society across communities, including the tracking of disease. However, local autonomy in decision making should be honored where there is no evidence to support a belief that centralized decision making is necessary to preserve the functioning of society and where the easing of restrictions in particular communities is proportional and reasonable (e.g., uniform duration of school closing may not be reasonable in communities where the influenza wave has already ended). Local decision makers should be prepared to make their reasoning transparent in these situations; they must be authorized to use their best judgment and supported in their efforts to do so.

In enacting any measure that limits personal freedom, the least restrictive, practicable, effective measure should be taken based on the best available evidence that the constraint will achieve its intended goal and that no less restrictive measure is likely to be as effective. An exception to this criterion may be justified if the less restrictive measure would be unduly burdensome (e.g., either too expensive or the agency responsible for implementation lacks the resources or expertise to implement).

Constraints should be enacted only if failure to implement the measure is likely to result in grave harm to the functioning of society or to the well-being of the public. For example, if quarantine is enacted, the duration of the quarantine should be clearly informed by transmission characteristics and should be as short as is medically justifiable. Home quarantine should be honored where reasonable and desired, and monitoring/surveillance should be as nonintrusive as possible.

When closure of public venues is being considered, decision makers should determine which venues are essential to the functioning of society and allow them to remain open, albeit with some constraints on level of access. For example, grocery stores may need to remain open with some new mechanism for distribution that will safeguard both fair access and decreased potential dissemination of disease (e.g., maximum order amounts or a delivery service). Other examples of possible "essential services" are pharmacies, public transportation systems, sanitation systems, gasoline stations, fire stations, and the police.

Agencies responsible for imposing restrictions such as quarantine, isolation, or other limitations must consider that the affected citizens, their families, and other dependents will require adequate access to food, water, and other essential services. Agencies should attempt to secure access to these requirements for the parties, and provide protection of the restricted individuals' jobs and their ability to meet economic obligations.

There should be no unwarranted invasions of privacy and the mechanisms for maintaining confidentiality of private information should be secure. Where information sharing is important to protect public health, measures that safeguard personal, private information should be in place and support should be given to ill individuals, family members, and others potentially stigmatized by real or potential illness.

Allocating Resources

Allocating resources during pandemic influenza will be complicated and, like restrictions on liberty, should be addressed well in advance. Pandemics are chaotic and uncertain, and there may be no consensus regarding mitigation tactics or the resolution of value conflicts, for example, whether or not to stockpile resources, or whether to maximize public welfare or fairness. Allocation planning will foster health literacy and provide information that all individuals can obtain, understand, and use effectively.

Allocation plans should

- provide a detailed list of vaccines and other goods that are considered scarce (e.g., antivirals for the purpose of treating or preventing influenza),
- specify what will not be covered by the distribution plan and why (e.g., drugs that treat or prevent certain disorders or conditions that make one more susceptible to contracting influenza),
- identify the office or agency that will make prioritization and distribution decisions,
- include a mechanism for interpretations of rules in cases of dispute or appeal, and
- clarify eligibility criteria. (Will all individuals present in the local community be eligible, regardless of visitor status? Will the local community encourage travelers to return to home communities to receive the scarce resource? Will exceptions be made? On what basis?)

Approaches that could impose suffering on a few for the benefit of many ought to be tempered by such principles as

- minimizing harm or injury to individuals and communities,
- within priority groups, providing equitable (i.e., fair) opportunity to access resources, and
- employing the least restrictive effective interventions.

The following allocation criteria are generally not ethically supported in pandemic planning and response:

- race, ethnicity, religious belief, gender, sexual orientation, or intelligence;
- to each according to his or her purchasing power;
- to each according to what he or she deserves; or
- first come, first served (because it puts certain groups, such as those who are less likely to be informed or those who have inadequate transportation, at a disadvantage).

In ordinary circumstances, the criterion, to each according to his or her social worth, is not ethically acceptable. However, in responding to pandemic influenza it may be necessary to identify certain individuals and groups as key to preserving society and to accord them a high priority for the distribution of certain goods (e.g., vaccines and antiviral drugs). “Keyness” is a social worth criterion that is justified in the limited circumstance of pandemic influenza response where the goal is to promote human life, safety, and the well-being of the community over time. Extreme care must be taken to avoid extending the evaluation of social worth to other attributes that are not supported by ethics. Key individuals in pandemic response may include healthcare workers, those responsible for essential services during the pandemic, and those who can help the community recover once the emergency has abated.

The pandemic influenza plans that hazard-resistant, resilient communities make for allocating scarce resources will anticipate the need to support citizens who do not meet the eligibility criteria for receiving scarce community resources. As previously noted, a full discussion of the healthcare ethics issues that are central to pandemic influenza has been reserved for a separate linked document. However, the prospect of citizens being unable during a pandemic to obtain healthcare as normally expected must be anticipated and, whenever practicable, pandemic response plans should explicitly provide alternative-to-healthcare supports. We believe, however, that the citizens of communities characterized by robust networks of mutual assistance will be best able to provide such alternatives. That is, when confronting the need to allocate scarce resources in response to pandemic influenza, community solidarity is as important as providing explicit support.

Meeting Special Needs

Vulnerability is partly a function of the capabilities and personality of individuals. However, it is also a function of the social systems and resources that limit individuals’ options and impair their ability to protect themselves in the face of danger or disruption. Moreover, vulnerability is not necessarily a global condition that characterizes all facets of an individual’s life. It is better understood as a notion that is specific to particular situations, problems, and tasks. Some persons and groups have background conditions and situations that compound their vulnerability to pandemic influenza and expose them to special kinds and degrees of risk and disruption. Anticipating and planning for special needs is an essential component of pandemic influenza planning.

Pandemic influenza preparedness and response cannot be a substitute for a broad, progressive effort to improve the services for those living with chronic illness and disability, for children, for

the elderly, for poor and minority persons who are underserved, or for those who need long-term care. But it can ensure that persons and groups with special needs are not forgotten or abandoned in times of crisis or emergency.

General plans about contacting and providing services to people with special needs are important, but in emergencies where transportation is difficult, and telecommunication unreliable, local emergency responders require precise local knowledge concerning persons with special needs and their physical locations. Advance registration programs and local neighborhood support networks can be helpful for this purpose.

It is important not to overgeneralize or base public health emergency preparedness and response on stereotypes or unexamined assumptions concerning persons or groups with special needs. Their attitudes, preferences, and resources are not all identical. Those responsible for public health emergency planning and response should

- provide culturally and functionally appropriate information to individuals with disability, their family members, and others who care for them about what to expect in times of emergency;
- recognize that public health measures designed to limit the spread of infectious diseases, such as social distancing, pose many problems for vulnerable populations; and
- ensure that people with special needs or vulnerabilities have opportunities to participate actively and directly in the processes of pandemic influenza preparedness and response.

Individuals and groups that have exceptional knowledge about persons with special needs or vulnerabilities or to whom special loyalty and trust have been accorded by these vulnerable persons should be integral to the processes of pandemic influenza preparedness and response. Compassionate caring and support should be provided to all members of society, regardless of their social, economic, or health status, or disability.

Communication and Deliberative Participation in Emergency Planning

Citizens have a right to be provided with truthful complete information so that they in turn can fulfill their civic and personal obligations in the context of a public health emergency. They also have the right to deliberate about and give informed participatory consent to decisions and policies that materially affect their own safety, health, and well-being.

Open, inclusive deliberative planning will build the necessary foundation of legitimacy and public trust required by a public health emergency preparedness and response effort and will also provide for feed-back and self-correcting mechanisms that will improve the efficacy of preparedness measures.

Grassroots participation in the emergency preparedness planning process can inform the process regarding cultural and other factors that professional planners may overlook. It can create a sense of investment in the plans that may lead to better community coordination and compliance later on. Planning should include providing resources for supervising, training, and effectively using volunteers.

Obligations to Health Workers, Healthcare Providers and Citizens

Health workers and healthcare providers may put themselves at risk in responding to pandemic influenza. Those who undertake these vocations imply their willingness to face some additional risk. The duty to assume occupational risk is hard to specify, but the nature, scope, and limits of an obligation to put oneself at risk during pandemic influenza needs to be addressed.

In addition to weighing their obligations to face personal risks, health workers and healthcare providers must also consider their obligations to their families and each other.

Missouri is obliged to provide health workers and healthcare providers with the protections and tools they need to respond to an influenza pandemic. This includes providing information, training, protective gear, and a sufficient infrastructure in which to do their jobs. Missouri is further obliged to care for these individuals if they become ill or disabled, and to compensate their families should they die.

Employers ought to consider implementing protective procedures and accommodations to ameliorate the impact of pandemic-related constraints on their employees' liberty (e.g., employers might offer day care to employees during school closures).

Citizens who provide essential services or who assist health workers or healthcare providers may also face personal risks and competing family obligations. Whether such citizens have heightened responsibilities and what the sources of such obligations might be should be considered during the planning process. Thought should also be given to how such citizens should be compensated for serving in times of crisis. Citizens who are immune (either from having survived the illness or from other means) may have a special role during the pandemic (i.e., they may be capable of doing work that would place other, nonimmune individuals in harm's way).

Civic Obligations and Personal Responsibility

Public health professionals and other leaders should use the planning process to strengthen the social capital of communities and to make them more resilient so that they can bounce back from disasters quickly and return to civic health.

Preparing for and responding to pandemic influenza is a civic activity, part of the basic purpose of forming a political community in the first place. It ought to be an expression by the entire community about the value of the lives and health of its members.

Civic renewal is a practical task. Citizens do not become involved in their communities unless they find the activities and issues meaningful to their own lives and believe their involvement will actually make a difference.

The capacity of individuals to respond and the capacity of communities to respond are interrelated.

The fact that preparing for and responding to pandemic influenza is a civic activity does not obviate the fact that there are also significant obligations incumbent on citizens.

Emergency planning ought to engage citizens in ways that renew or strengthen their sense of civic responsibility and membership. Participation in planning should also invigorate those neighborhood and community organizations that comprise the infrastructure for recovery from disaster and dislocation.

Planning can help health workers, healthcare providers, and citizens confront an anticipated public health emergency. But planning alone will not be sufficient to ensure success. Ultimately individuals must take responsibility for how prudently and responsibly they act to protect themselves and their families.

Public health emergency planning should assume a measure of self-protection and personal responsibility on the part of ordinary people, and it should give them the information they need to make informed choices.

Planning must also accommodate the reality of limited choices and resources that many people confront in their normal lives, for these will constrain them before, during, and after an emergency as well.

Fair Process

Since there does not appear to be a single right answer to or any clear societal consensus regarding the proper weight that should be attributed to conflicting values during public health emergencies, it is crucially important to develop a fair process that will both effectively engage the public in planning and lend moral legitimacy to the results of deliberation. Even if there is no consensus on a single correct way to balance efficiency and equity, we can perhaps achieve a greater degree of consensus on what would be a fair process for coming to a decision. Lacking ethical certainty on the right outcomes, we should seek ethical consensus on fair and appropriate procedures for setting priorities and allocating scarce resources.

The elements of fair process include accessibility, transparency and publicity, an appeals process, and active engagement with stakeholders.

Conclusion

We believe that this paper can be a resource for ongoing, serious conversation and deliberation about ethics. Our goal was not to provide premature guidance and conclusiveness, but to promote ethical reflection and reasoning precisely at a time when we do not fully understand everything there is to know about how to do emergency planning and disaster preparedness. As the epidemiological, clinical, and behavioral sciences are still on a learning curve in the field of public health emergency preparedness and response, there is still much to be learned about the ethics of preparing and responding to pandemic influenza. Still, the ethical framework provided here can help individual, community, and regional decision makers develop more specific guidelines. It may also be used to help preserve and respect the integrity and efforts of all participants. If it does this, then both our ethical and practical efforts will likely be successful.

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Consortium of Missouri Health Ethics Organizations

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