

National Collaborating Centre
for **Healthy Public Policy**

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PUBLIC HEALTH ETHICS – SELECTED RESOURCES: ETHICS IN A PANDEMIC

INVENTORY | MAY 2010



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ABOUT THE NATIONAL COLLABORATING CENTRE FOR HEALTHY PUBLIC POLICY

The National Collaborating Centre for Healthy Public Policy (NCCHPP) seeks to increase the expertise of public health actors across Canada in healthy public policy through the development, sharing and use of knowledge. The NCCHPP is one of six Centres financed by the Public Health Agency of Canada. The six Centres form a network across Canada, each hosted by a different institution and each focusing on a specific topic linked to public health. In addition to the Centres' individual contributions, the network of Collaborating Centres provides focal points for the exchange and common production of knowledge relating to these topics.

ABOUT THIS PUBLICATION

Public health ethics (PHE) is a relatively new field of study that encourages interdisciplinary discussion of moral issues related to the theory and practice of public health and preventive medicine. Emerging over the last 15 years out of dissatisfaction with the traditional orientations of biomedical ethics, PHE involves the explicit use of concepts from ethical, social and political theory to discuss and evaluate collective interventions that aim to protect and promote the health of groups and populations rather than of individuals.

This document has two aims. The first is to serve as a timely introduction to the field of PHE as applied to policy and practice responses to what was perhaps the most visible recent global public health threat, the global influenza AH1N1 pandemic. It is based on a review of the literature on this subject carried out by the National Collaborating Centre for Healthy Public Policy (NCCHPP) between May and August of 2009. The review does not claim to be exhaustive of the full range of information and resources available at the time it was carried out. Rather, it seeks to select from among that range a collection of relevant, representative, and accessible works that together provide a foundation for exploring the ethical implications of infectious disease control and pandemic response. The focus is thus to provide a type of primer for further reflection and discussion, and possibly for subsequent dispatches or briefing notes, of the variety of moral dilemmas likely to arise during an influenza pandemic. These include but are not limited to health care professionals' duty to care, resource allocation and priority setting during emergencies, imposing restrictive measures, social distancing, and quarantine in practice, international public health obligations, risk perception and communication, and public health research ethics.

The second aim of this document is to serve as a precursor to the development of a pan-Canadian Public Health Ethics Portal and an inventory (of resources, researchers, educators, projects and literature) to be hosted by the NCCHPP. There is currently no centralized and up-to-date repository of such information, despite an ever-increasing interest in the ethics of public health. The Centre's aim is therefore to build and reinforce links among public health practitioners, researchers, policy makers and educators, and to create an online library of resources and space for dialogue, information-exchange, and collaboration. Given recent events involving influenza outbreaks (both H5N1 and AH1N1), a focus on ethical decision-making during a pandemic seems a timely and useful starting point. However, the long-term objective remains to create a platform for ongoing discussion of core values and concepts and ethical issues related to all aspects of public health policy and practice. This may include infectious disease control more broadly and other "traditional" topics (such as epidemiological research, health promotion, screening, population genetics, vaccination, environmental health, and lifestyle risk factors), as well as those that derive from a broader vision of the determinants of health and the scope of public health practice (like advocacy for social equity and justice, resource allocation, health in all policies and other interdisciplinary and intersectoral initiatives, and global health).

Included here is a selection of tools intended to facilitate access to resources, stimulate reflection, encourage discussion, and build connections and encourage knowledge sharing among people – from the social science fields of philosophy, law, economics, and policy

studies in addition to the field of epidemiology and the medical sciences – engaged in the practical and theoretical work of protecting and promoting the health of populations. These are:

- Short summaries of a selection of seminal papers, frameworks and guidelines;
- Links to additional resources on ethics and pandemics, including articles, presentations, case studies and other learning tools, and pertinent websites, blogs, and news sources;
- Hyperlinks leading directly to the resources listed (priority has been given to open source or publicly available documents).

Since resources are revised and hyperlinks change, we encourage you to draw our attention to any errors, omissions, or new materials by e-mailing christopher_w.mcdougall@inspq.qc.ca. We also welcome your comments more generally on the usefulness of this primer and of any other initiatives or approaches to knowledge translation in the area of applied public health ethics.

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1 OVERVIEW OF ETHICS DURING PANDEMICS

Public health ethics is currently the subject of a surge of interest, and no small portion of that is due to the challenges involved in confronting recent outbreaks of new and re-emerging infectious diseases. Over the past decade or so, and perhaps particularly since the development of effective human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) treatments and in the aftermath of severe acute respiratory syndrome (SARS), health professionals, academics, and policy makers have increasingly grappled with the moral dimensions of protecting and promoting the health of populations. The general aims of public health are clearly distinct from those of clinical medicine due to a preventive and collective focus, which may require active interventions by government that involve major burdens or limitations on the rights of individuals and groups. Public health ethics is thus more community-oriented than medical ethics and is relevant to the day-to-day lives of citizens, when they choose or choose not to act in ways that may expose others to the risk of infection, for example, or to have themselves or their children immunized.

When a particular infectious disease begins to affect a larger than usual number of people, or to circulate globally among populations that have little immunity (as happened most recently with influenza AH1N1), the specific aims of public health require that very difficult decisions be made. They are likely to have to be made, moreover, as many people become sick and some die, and under conditions of significant uncertainty, panic, time pressure, and high demand amid widespread shortages. Trade and travel restrictions, quarantines, school closures, bans on public gatherings, staffing management and workplace safety assurances, testing of newly developed vaccines (particularly with vulnerable populations), reliability of different diagnostic tests, emerging resistance to pharmaceuticals, and the allocation of scarce medical and material resources are just some of the pressing issues that all societies will face during an influenza pandemic.

Although ethical principles and frameworks for decision making cannot provide definitive answers to these and other dilemmas and value conflicts that arise during a crisis such as an influenza pandemic, they can help both individuals and policy-makers make good decisions in difficult times. Moral theories and concepts draw attention to and encourage debate on the variety of ends, goals, and means that can be adopted in preparing for and responding to public health emergencies. Different approaches to and strategies for balancing rights and obligations in the context of an emergency demonstrate the need to be explicit, transparent and accountable when justifying inevitably difficult trade-offs and choices that can also cause some harm. Shared values, finally, provide a basis for assessing various alternative actions in any specific situation, and a platform for enabling cooperation and coordination across a wide range of situations, both of which are necessary if communities are to responsibly navigate their way through the pandemics of today and of the future.

Public health, both as a measure of the community's well being, and as the constellation of societal practices that protect and promote that well being, has changed dramatically over the past 100 years. Public health ethics is integral to the project of bridging the gaps between the scientific, the social, and the political facets of public health to make sure that it continues to improve for the next 100 years.

1.1 SELECT REFERENCES

1.1.1 Brief Overviews of Ethics in a Pandemic (open-access materials)

- 1.1.1.1 University of Toronto Joint Centre for Bioethics. Pandemic Influenza Working Group. (2005). *Stand on Guard for Thee: Ethical considerations in preparedness planning for pandemic influenza*. Retrieved from: http://www.jointcentreforbioethics.ca/publications/documents/stand_on_guard.pdf

This report proposes a comprehensive ethical guide to planning for and responding to major communicable disease outbreaks, such as pandemic influenza. The guide was developed with expertise from clinical, organizational, and public health ethics, and it was validated through a stakeholder engagement process within the health care sector that included hospital staff and administrators, government officials in public health and long term care, voluntary organizations, and foreign and international health agencies. It provides a framework for identifying, evaluating and balancing ethical considerations in pandemic influenza planning and response. The authors note that while it is difficult to implement and balance principles during a crisis, there are major risks in not having an agreed-upon ethical framework in place prior to a crisis, including loss of trust, low morale, fear and misinformation. The report also cautions that there is no single clear answer to such issues for any or all jurisdictions or localities.

The Stand on Guard for Thee Framework has been integrated into pandemic plans in Canada and other countries. It has received considerable press coverage, and has also informed a World Health Organization consultation on ethical issues related to pandemic planning (see section 1.1.5.1). The report provides clear descriptions of the ten substantive and five procedural values that make up the framework, which is viewed as a package of interdependent values important in any democratic society:

- Individual liberties
- Protection of the public
- Stewardship
- Inclusiveness
- Responsiveness
- Accountability
- Reasonableness
- Transparency
- Trust
- Solidarity from harm
- Proportionality
- Privacy
- Duty to provide care
- Reciprocity
- Equity

In an effort to illustrate how these principles can be used in practice to reflect on concrete dilemmas and justify specific policies or decisions, *Stand on Guard for Thee* also provides extended discussions of four key issues that emerged from experiences during the SARS crisis, and makes recommendations in relation to each of the following:

- The **duty to care of health care workers** and the **reciprocal obligations of institutions** to health care workers,
- The legitimacy of the use of **restrictions of civil liberties** in the interest of public health,
- **Fair allocation of scarce resources, and**

- Issues in **global governance and obligations to other states.**

1.1.1.2 Torda, A. (2006). Ethical issues in pandemic planning. *Medical Journal of Australia*, 185(10 Suppl.), S73-S76. Retrieved from: http://www.mja.com.au/public/issues/185_10_201106/tor10900_fm.html

Through an accessible discussion of a scenario in which quarantine is considered for an entire inbound flight on which several passengers report flu-like symptoms (a likely starting point for an outbreak of pandemic influenza in Australia), this article surveys ethical issues related to health risk assessment, resource allocation, and hospital management decisions. Emphasizing that many decisions will be controversial (including rationing of antivirals, allocation of hospital beds and vaccinations, and acceptable occupational risk levels, and staff duties and rostering, among others), the author recommends that pandemic planning be undertaken well in advance, that it be broadly inclusive, and that it be framed by a clear ethical framework so as to optimize acceptance of decisions by health care workers and other members of an affected community.

The Toronto Joint Centre for Bioethics framework introduced above is simplified and used to facilitate discussion of the scenario. The following set of management principles is recommended to guide decision making in pandemic planning and response:

- **Act on the best available evidence,**
- Ensure **transparency** of decision making,
- Maintain **open and regular communication,**
- **Protect workers** involved in providing care,
- Be **sensitive to cultural requirements & practise inclusive** decision making,
- Be **accountable and responsible,** and
- Embed **consultation, review and responsiveness** in the decision-making process.

1.1.1.3 Members of the Bellagio Group. (2006). *Bellagio Statement of Principles*. Meeting on Social Justice and Influenza, 24 July to 28 July 2006. Retrieved from: <http://www.bioethicsinstitute.org/web/page/906/sectionid/377/pagelevel/4/interior.asp>

This text is a review of the ways in which a pandemic could have a disproportionately negative impact on socially and economically disadvantaged groups. It was written by an international group of experts in diverse fields, such as public health, animal health, virology, medicine, public policy, economics, bioethics, law, and human rights. The purpose was to consider and deliberate on questions of social justice and the threat of pandemic influenza. The group's consensus is that efforts to prepare for and respond to the threat of an influenza pandemic should take account of the needs and interests of the world's disadvantaged communities by incorporating considerations of social justice in pandemic planning response. The group also developed a series of checklists that aid in incorporating these principles into preparedness and response efforts, and urges policy makers and health officials to:

- Specifically **make accurate, up-to-date, and easily understood information** about avian and human pandemic influenza available for disadvantaged groups,

- Actively **seek input from traditionally disadvantaged groups**, followed by deliberate sharing of planned public policy responses with such groups,
- Significantly **increase the degree of public involvement** in the surveillance and reporting of possible cases, without fear of discrimination or uncompensated loss of livelihood, and
- Identify and address any obstacles that disadvantaged groups may face in benefiting from preparedness plans.

1.1.1.4 American Civil Liberties Union. (2008). *Pandemic Preparedness: The Need for a Public Health – Not a Law Enforcement/National Security – Approach*. Retrieved from: <http://www.aclu.org/technology-and-liberty/pandemic-preparedness-need-public-health-%E2%80%94-not-law-enforcementnational-securi>

The American Civil Liberties Union examines the relationship between civil liberties and public health in contemporary U.S. pandemic planning and makes a series of recommendations for developing a more effective, civil liberties-friendly approach. Part one reviews the historical context of this relationship, examining in particular the disastrous consequences of public health policies built around a vision of sick people as the enemy. Part two summarizes post-9/11 plans intended to protect the nation against a possible influenza epidemic and how these plans relied upon the false premise that public health is a law enforcement or national security problem that can be solved by limiting the rights and liberties of affected individuals. Part three provides a series of recommendations for an improved paradigm for pandemic preparedness, one that protects both public health and civil liberties through open and transparent public communication. The rationale for transparency has public health, strategic, and ethical dimensions. Despite this, government authorities often fail to demonstrate transparency. A key step in bridging the gap between rhetoric and reality is in defining and codifying transparency to put practical mechanisms in place that encourage open public health communication for emergencies. The authors demonstrate this approach using the example of the process of developing and implementing a public health emergency information policy. Based on that example, the report calls for a new ethical paradigm for pandemic preparedness based on the following principles:

- **Health** — The goal of preparing for a pandemic is to protect the lives & health of all.
- **Justice** — Preparation for a potential pandemic (or any disaster) should ensure a fair distribution of the benefits and burdens of precautions and responses and equal respect for the dignity and autonomy of each individual.
- **Transparency** — Pandemic preparedness requires transparent communication of accurate information among all levels of government and the public in order to warrant public trust.
- **Accountability** — Everyone, including private individuals and organizations and government agencies and officials, should be accountable for their actions before, during and after an emergency.

- 1.1.1.5 O'Malley, P., Rainford, J., & Thompson, A. (2009). Transparency during public health emergencies: from rhetoric to reality. *Bulletin of the World Health Organization*, 87(8), 614-618. Retrieved from: <http://www.who.int/bulletin/volumes/87/8/08-056689.pdf>

Noting that government authorities often fail to demonstrate transparency, despite its importance on public health, strategic and ethical grounds, the authors provide an organizational policy model by which authorities can put in place practical mechanisms to encourage open public health communication during emergencies. The model encourages the explicit identification of transparency as a desired communication goal and outcome and the acknowledgement of limits to transparency such that certain types of information may be legitimately withheld on security, privacy, or public health grounds. The authors provide a list of questions designed to assist officials in deciding whether or not to release information, as well as guidance on dissemination tactics, in their communication plans for reaching the appropriate audiences with the information needed and sought during the course of an emergency, and for tailoring information to these audiences' specific contexts and communities.

In deciding whether or not to release a given piece of information, public health officials are advised to ask three questions, bearing in mind that the core public health imperative of informing those at risk must always take priority:

- Is the information needed by at-risk parties to avoid illness, reduce the spread of a disease and/or help cope with the impact of an event?
- Is the information relevant to decisions made by public health authorities or about the emergency management decision-making process itself?
- Is there a compelling reason to withhold or modify the information, such as concern for compromising national security, a police investigation, privacy laws and/or confidentiality policies, or the safety of specific ethnic groups or people in specific geographical regions?

1.1.2 Slide Presentations on Ethics in a Pandemic

- 1.1.2.1 Guerrier, M., Reis, A., Upshur, R.E.G.(2009). *Ethics in public health policy development and research for A/H1N1 influenza*. [PowerPoint presentation]. Presented at a World Health Organization Ethics in a Pandemic meeting in Geneva. Retrieved from: http://canprep.ca/WHO_nov_20_2009_marcG.ppt

This is a review and update on developments related to seven pressing ethical challenges that have emerged during the planning for and response to the 2009 swine flu pandemic:

- Conducting research during an infectious disease outbreak,
- International sharing of information and biological samples,
- The uncertain clinical evidence base for public health interventions,
- Health care workers' rights and duties,
- Priority setting and access to resources,
- Varying standards for imposing distancing measures, and
- Maintaining public trust and confidence.

Emphasis is placed on making explicit the ethical underpinnings of public health needs, research, and practices. An overarching conclusion is that more interdisciplinary discussion and research is needed on each of these issues as well as across them.

- 1.1.2.2 Upshur, R.E.G., Faith, K., Thompson, A., Gibson, J. L. (2005). *Pandemic Influenza Planning: Ethical Framework*. [PowerPoint presentation]. Presented at University Health Network, Toronto. Retrieved from: http://www.jointcentreforbioethics.ca/publications/documents/pandemic_influenza.pdf

A concise and useful introduction to what is called “a moral compass” for public health decision-making during a crisis, this presentation provides background on the development of the Joint Centre for Bioethics’ Stand on Guard for Thee Framework. A review of the need and justification for the framework, and some pertinent literature on approaches to triage, the impact and aftermath of SARS, and fair decision-making processes is provided. This is followed by a brief, accessible definition of each of the 10 substantive and 5 procedural values introduced in 1.1.1.1.

- 1.1.2.3 Jiwani, B. (2001). *Ethics and Influenza Pandemic Planning*. [PowerPoint presentation]. Presented to a working group of the Alberta Interdepartmental Pandemic Influenza Committee, Edmonton. Retrieved from: <http://www.phen.ab.ca/pandemicplanning/Ethics&Pandemic.pdf>

This presentation offers a wide-ranging introduction to the field of moral theory designed to raise questions about the various issues that are likely to arise in the process of planning for a public health emergency. Through more than 50 slides, augmented by copious notes, the presentation provides a pragmatic view of the value, use, and limits of ethics, as well as of the relationship of ethics to health care and law, and of what makes actions justifiable. There is an excellent review of the importance of public participation and of the general consensus that decision-making must be based on human equality and transparent processes. An extended discussion of how different moral theories (and particularly utilitarianism and deontology) help illuminate the complexity of resource allocation at both the individual and policy levels is rich with insights about how different views on utility, equity and justice can contribute to actual public health decision making. The presentation also provides an overview of ethical issues for professionals (such as conscription or vaccination), for patients (such as demands for inappropriate care or refusals to comply with preventive measures), and for the public (such as communication) during a pandemic. In conclusion, the presentation reviews an approach to organizational ethics and policy in health care institutions that can address “moral distress” and create “a healthy ethical environment.”

1.1.3 Decision-Making Guides and Tools (open-access materials)

- 1.1.3.1 Thompson, A., Faith, K., Gibson, J. & Upshur, R.E.G. (2006). Pandemic influenza preparedness: an ethical framework to guide decision-making. *BMC Medical Ethics*, 7(12). Retrieved from: <http://www.biomedcentral.com/1472-6939/7/12>

Aiming to be an example of practical ethics that provides key decision makers with an introduction to and articulation of generally accepted ethical principles/values, this article is an early re-evaluation and refinement of the 15-principle Joint Centre for Bioethics’ Stand on

Guard for Thee Framework (see section 1.1.1.1). The guidance is specifically targeted at preparedness and policy decision making within health institutions, and is based on the work and deliberations of a hospital pandemic influenza planning committee. The authors discuss two issues (triaging of ventilated beds in an ICU and prioritizing populations for vaccine, and antivirals) to show how values can be embedded in planning assumptions and how the implementation of principles is not straightforward, but requires ethical reflection about what constitutes the upholding of general and specific moral obligations. They also identify three necessary, if not exhaustive lessons for implementing the use of an ethical framework in hospital pandemic planning processes. These elements are:

- **Sponsorship of the ethical framework by senior hospital administration** — Ensuring that institutional "sponsors" are in favour of adopting an ethical framework is important for gaining widespread support for using an ethical framework in decision making, and for ensuring that the ethical framework does not become something that looks good but remains unused,
- **Vetting of the framework by key stakeholders** — While it may not be pragmatic for hospitals to undertake broad public consultation and vetting processes for their pandemic plans in general, and their ethical frameworks in particular, solidarity and equity suggest that those who will be affected by decisions be consulted, and opportunities for broader ethical dialogue about pandemic planning be encouraged,
- **Formalized decision review processes** — An important aspect of fair, responsive, and morally legitimate decision-making processes is ensuring that there are formal opportunities to revisit and revise decisions as new information emerges.

1.1.3.2 Community Ethics Network. (2008). *Ethical Decision-Making in the Community Health and Support Sector*. Retrieved from: http://www.jointcentreforbioethics.ca/partners/documents/cen_toolkit2008.pdf

This document presents a community-based approach to ethics. It aims to increase awareness and understanding of front-line ethical dilemmas in public health, and to put forward a common framework for decision making based on ten principles, including advocacy, dignity, safety, and fair and equitable access.

The Community Ethics Toolkit proposes a Code of Ethics for Community Care, a decision-making worksheet, and guidance on using both in the field, for case reviews, and for teaching purposes. The *IDEA Ethical Decision-Making Worksheet* provides a step-by-step tool to assist in the process of resolving an ethical dilemma. It is composed of four sections (*Identify the Facts, Determine the Ethical Principles in Conflict, Explore Options, and Act on Your Decision and Evaluate*) that encourage users to address complex challenges in a comprehensive and logical manner that generates reflection, justification, action, and evaluation. This tool is available at: <http://www.jointcentreforbioethics.ca/partners/documents/EDM%20Worksheet%20Aug%202008%20Protected.xls>.

These documents are written in plain language, and are an excellent introduction and tool for integrating ethical reflection into public health decision-making, particularly at the clinical level.

- 1.1.3.3 Kass, N. E. (2005). An Ethics Framework for Public Health and Avian Influenza Pandemic Preparedness. *Yale Journal of Biology & Medicine*, 78, 235-250. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2259154/>

A readable review of the history of and links between public health, bioethics, and decision-making frameworks, this article proposes a six-step sequential guide for evaluating public health proposals, whether they are programs, interventions, research protocols, or policies. Designed to be an analytical tool to help professionals consider the ethics implications of their work (rather than a code of more general values and norms), the framework contains the following questions:

- 1) What are the proposed health goals?
- 2) How effective is the proposal in achieving its stated goals?
- 3) What are the known or potential burdens of the proposal?
- 4) How can those burdens be minimized? Are there alternatives to achieve the same goals?
- 5) Will the proposal be fairly implemented?
- 6) How can the benefits and burdens be balanced? What procedures will best allow for the fair consideration of differing views?

Part two of the article provides examples of how the framework could be applied to help navigate the extraordinary challenges of an influenza pandemic. The analysis is not exhaustive, but provides a potentially useful model for structuring the “thinking through” of some of the pressing ethical issues raised by a public health crisis, including the articulation of overarching goals of preparedness and response, the distribution of resources, the support needed by those who are isolated, and public disclosure of information.

- 1.1.3.4 Upshur, R.E.G. (2002). Principles for the Justification of Public Health Intervention. *Canadian Journal of Public Health*, 93(2):101-103. Retrieved from: <http://journal.cpha.ca/index.php/cjph/article/download/217/217>

An early review of the then-scant literature on principles relevant to ethical deliberation in public health, this paper argues that the application of the principles of clinical ethics (autonomy, beneficence, non-maleficence and justice) is not appropriate in public health practice. The author then identifies and discusses four different principles more relevant to public health: **the Harm Principle, the Principle of Least Restrictive Means, the Reciprocity Principle, and the Transparency Principle**. These principles are applied in practice to two cases, one involving a homeless non-compliant tuberculosis patient, and one involving an inconclusive investigation of community concerns about environmental contamination. These cases demonstrate that a different and differential standard of evidence may be required for public health actions. This is because despite the fact that empirical knowledge in the field is often uncertain, public health interventions may be appropriate regardless, given the magnitude of potential harms or the vulnerability of those affected. Further research and debate on the appropriate ethics for public health are encouraged.

- 1.1.3.5 United States Institute of Medicine. (2009). *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations*. Retrieved from: http://www.nap.edu/catalog.php?record_id=12749

This report is the product of a workshop convened at the request of the U.S Department of Health and Human Services to explore current concepts and guidance that can assist state and local public health officials, health care facilities, and professionals in the development of systematic and comprehensive policies and protocols for crisis standards of care in disasters where resources are scarce. The workshop participants were asked to discuss what types of policies and protocols with regard to standards of care would best serve to protect the public's health in the event that the 2009 AH1N1 virus had become a public health emergency in which thousands or even hundreds of thousands of people suddenly needed and sought medical care in communities across the country, stressing the health system to its limits. A vision of fair, equitable, and transparent crisis standards of care is provided, including criteria for determining when crisis standards of care should be implemented, key elements that should be included in crisis standards of care protocols, and criteria for determining when these standards of care should be implemented. The criteria and key elements are based on the following principles:

- **Fairness** — requires that standards be, to the extent possible, evidence-based, responsive to needs, and acceptable to all those affected, while respecting duties to ensure compassion, care, resource stewardship, and maintenance of public and patient trust.
- **Equitable processes** — requires that standards be the result of decisions made transparently and with accountability, as well as applied consistently (without discrimination) and in proportion to the scale of the emergency and the degree of scarcity.
- **Active collaboration** — requires input through formalized processes from the public and stakeholders in order to ensure community and provider engagement, education, and communication.
- **The rule of law** — requires that appropriate actions, standards and incentives are made by appropriate authorities through appropriate processes and laws.

The report takes it as a given that shortages of critical resources will change the level of care it is possible to deliver, and seeks to develop conditions, procedures, and tools by which such changes can be implemented by clinicians, health care institutions, and state and local public health officials in a disaster situation. The report is thus focused on articulating a uniform and clear but flexible national framework that can be generalized to all crisis events in which health care resources are overwhelmed, but which specifies that any change to the level of care delivered must be justified by specific circumstances and formally declared by public authorities. To that end, the report makes six recommendations:

- Develop consistent state crisis standards of care protocols,
- Seek community and provider engagement,
- Adhere to ethical norms when crisis standards prevail,
- Provide legal protections for health care practitioners and institutions implementing crisis standards of care,

- Ensure consistency in crisis standards of care implementation,
- Ensure intrastate and interstate consistency among neighbouring jurisdictions.

1.1.4 Other Selected Resources

- 1.1.4.1 Childress, J. F., Faden, R. R., Gaare, R. D., Gostin, L.O., Kahn, J., Bonnie, R. J. Kass, N.E., Mastroianni, A. C., et al. (2002). Public Health Ethics: Mapping the Terrain. *The Journal of Law, Medicine & Ethics*, 30(2002), 170-178. Retrieved from: <http://www2a.cdc.gov/phlp/docs/cdc.childress.web.pdf>

In this article, Childress et al. provide a conceptual map of the terrain of public health ethics. They highlight the general moral considerations of justice, autonomy/liberty, and privacy/confidentiality as particularly relevant to public health. Conflicts between moral considerations may occur when their scopes overlap. The weight given to a particular moral consideration will help determine which moral consideration yields in cases of conflict. Childress et al. describe a set of five "justificatory conditions" to help address situations in which the goals of public health conflict with other moral commitments: effectiveness, proportionality, necessity, least infringement of general moral considerations, and public justification. The authors also highlight the contributions of theories on paternalism, social justice, and human rights to ethical issues in public health.

- 1.1.4.2 Kotalik, J. (2005). Preparing for an Influenza Pandemic: Ethical Issues. *Bioethics*, 19(4), 422-431. Retrieved from: http://www.hsph.harvard.edu/hcphp/files/Kotalik_-_Preparing_for_Pan_Flu_Ethical_Issues.pdf

An early and influential ethical analysis of the pandemic plans of Canada, the United Kingdom, and the United States, which are viewed as major, historically unique public health initiatives. The author is particularly concerned about an overall lack of detailed concrete estimations and planning with regard to reducing and managing the presumed scarcity of human and material resources, to ensuring the equitable distribution of vaccines and antivirals, and to seeking inclusiveness, transparency, and reciprocity across planning and communication processes. The fact of epidemiological uncertainty at the outset of most outbreaks is seen to support the development of a spectrum of severity scenarios, as has since been done in most national planning documents.

The author's recommendations on wider public and professional consultation and communication strategies come in the form of a seven-step planning process that seeks to integrate scientific and moral deliberation so as to generate informed and broadly-accepted policy, including reassurances that authorities will aim to protect and support health care workers in a way that corresponds to the demands made on them. Such recommendations are in turn embedded in a critique of the assumption of scarcity, pervasive in pandemic planning but uncommon in the literature, which the author views as the product of other upstream policy decisions less clearly linked to the science of pandemic planning but with crucial implications for achieving the goals of pandemic response and respect for values (especially in the event of a more severe crisis). The article suggests that avoiding a frank discussion and justification of the acceptability of certain human costs during a pandemic is

irresponsible, and hinders the creation of an atmosphere of mutual trust and solidarity, qualities that will be much needed during a pandemic.

- 1.1.4.3 Roberts, M.J. & Reich, M.R. (2002). Ethical analysis in public health. *The Lancet*, 359(9311), 1055-1059. Retrieved from: <http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2802%2908097-2/abstract> (*Free full text, but registration required*)

This article develops an approach to analyzing serious public health ethical dilemmas that combines three philosophical views often invoked in public health discourse: positions based on outcomes (utilitarianism), positions focused on rights and opportunities (liberalism), and views that emphasize character and virtue (communitarianism). The article explores critical variations within each position, and identifies practical problems that arise in addressing the ethical dimensions of health policy. The authors also draw attention to the challenges posed by feminist ethics-of-care arguments and by postmodern views about the nature of ethics. They conclude by suggesting that health professionals need enhanced skills in applied philosophy to improve the coherence, transparency, and quality of public deliberations over ethical issues inherent in health policy.

- 1.1.4.4 Ezekiel, J. & Wertheimer, E. A. (2006). Who Should Get Influenza Vaccine When Not All Can? *Science*, 312, 854-855. Retrieved from: <http://sciencemag.org/cgi/content/short/312/5775/854> (*Subscription required*)

This short paper examines vaccine rationing in the event of an avian influenza (bird flu) outbreak and proposes a controversial principle for helping to make rapid, ethically sound decisions about who should get limited medical resources. Noting that existing vaccine manufacturing capabilities mean that supplies will be extremely limited in the early stages of a pandemic, the authors suggest that existing policy guidance in the U.S. (which gives priority to vaccine workers, health-care providers, and the elderly ill, placing them at the top of the list, and which places healthy people aged 2 to 64 at the bottom) is ethically and practically inadequate. The authors instead advocate prioritizing 13-40 year olds before infants, children and the elderly, thereby “saving the most life-years” rather than the most lives. Their alternative framework for priority ranking of access to influenza vaccine draws on a combination of two principles:

- A **life-cycle allocation principle**, which is based on the idea that each person should have an opportunity to live through all the stages of life (to be a child, a young adult, and then to grow old), informed by the observation that death seems more tragic when a child or young adult dies than when an elderly person dies. It is meant to be egalitarian in that a person's productivity to society and/or contribution to others' well-being does not factor in to the determination. The authors propose an investment refinement for this principle, which gives priority to people between early adolescence and middle age on the basis of the amount the person has invested in his or her life balanced by the amount left to live.
- A **public order principle**, which focuses on the value of ensuring safety and the provision of necessities, such as food and fuel.

Together, these two principles lead the authors to the "investment refinement combined with the public-order principle" (IRPOP), which they say emphasizes people between 13 and 40 years of age - while also giving high priority to vaccine production and distribution workers, as well as health care and public health workers with direct patient contact. IRPOP is meant to serve as a vaccine dissemination strategy. A good summary of the debate to which this article responds is provided in *The Allocation of Vaccines during an Influenza Pandemic*, which is available at: http://www.vaccineethics.org/issue_briefs/pandemic.php. IRPOP has also been identified as a potential tool for the allocation of other tragically limited resources in the event of a pandemic experience like avian flu, as in this bioethics briefing note, *Flu Pandemic and the fair Allocation of Scarce Life-Saving Resources*, which provides links to other readings and summarizes six additional ethical options for rationing during a pandemic. This document is available at: http://www.thehastingscenter.org/pdf/avian_flu_back_grounder.pdf.

1.1.5 Overviews of Ethics and Policy Issues in a Pandemic (open access)

1.1.5.1 World Health Organization (WHO). (2007). *Ethical considerations in developing a public health response to pandemic influenza*. Retrieved from: http://www.who.int/csr/resources/publications/WHO_CDS_EPR_GIP_2007_2c.pdf

This short, minimally prescriptive report might best be understood as a tool designed to raise awareness and improve the quality of pandemic planning. The report summarizes the background papers and discussions of four working groups, convened in 2006 at the request of WHO Member States to develop guidance on ethical issues in developing and implementing pandemic influenza response plans. The report directly acknowledges that ethics cannot provide a prescribed set of policies, and instead seeks to provide practical guidance on how to incorporate ethical (and related legal and human rights) considerations into plans, preparations and responses to pandemic influenza. The text begins by providing a glossary (pages v-vi) in which a number of plain-language definitions for key relevant principles are offered (including equity, utility/efficiency, liberty, reciprocity, and solidarity), before briefly discussing the following five "general ethical considerations":

- **Balance rights, interests, and values** — competing claims based on different principles must be accessed through ethical deliberations designed to reach appropriate decisions, which, if they infringe on individual liberties, must be necessary, reasonable, proportional, equitable, non-discriminatory, and legal.
- **Use best available evidence, but remain flexible** — because little may be known for certain about a pandemic in its early phases, judgments about public health measures must be made based on their likely effectiveness and benefits, but they must also be constantly re-evaluated in light of new evidence.
- **Seek transparency, public engagement, and social mobilization** — all aspects of planning should involve relevant stakeholders, and policy decisions and their justifications should be publicized and open to public scrutiny in order to foster public awareness, confidence, assent, feedback on local conditions, trust, legitimacy and compliance.

- **Inform, educate, and communicate** — advance planning is needed to develop strategies to reach the entire population in linguistically and culturally appropriate ways during all phases of pandemic preparedness and response (and especially to enable public participation in policy development, and public understanding both of the risks related to pandemic spread, and of the individual and collective measures that are justified and appropriate to respond to those risks).
- **Justify resource constraints and allocations** — although what count as “reasonable efforts to prepare” for a pandemic will vary according to the available resources and competing health priorities in any specific country, difficult allocation decisions (including contributions to the international cooperation necessary to overcome resource constraints in developing countries) should be informed by public engagement processes and have clearly communicated rationales.

Noting that “specific decisions will depend on local circumstances and cultural values” and thus that this global guidance must necessarily be adapted to the “regional and country-level context, with full respect to the principles and laws of international human rights” (page 2), the WHO report goes on to discuss the following four ethical challenges in more detail, including reviews of general governmental responsibilities, broad ethical considerations and specific decision-making criteria, as well as illustrative extracts from plans and processes from a variety of countries. (A useful set of references, and an additional bibliography containing a series of links to key internet resources, are also provided.) The four ethical challenges are:

- Priority setting and equitable access to therapeutics & prophylactics,
- Isolation, quarantine, border control and social-distancing measures,
- The role and obligations of health-care workers,
- Developing a multilateral response to an outbreak of pandemic.

1.1.5.2 United States Institute of Medicine. (2007). *Ethical and Legal Considerations in Mitigating Pandemic Disease: Workshop Summary*. Retrieved from: http://www.nap.edu/catalog.php?record_id=11917

This free online e-book summarizes and synthesizes the presentations and discussions of a group of experts convened at a 2006 public workshop exploring lessons learned from past pandemics, identified barriers to equitable and effective responses to future pandemics, and examined opportunities to overcome these obstacles through research, policy, legislation, communication, and community engagement. Building on previous meetings on the scientific and logistical challenges associated with pandemic disease recognition, identification, and response, participants recognized the difficulty of implementing disease control strategies effectively and, at the same time, fairly and justly.

Since many disease mitigation strategies may have unintended—and often undesirable—consequences (such as adverse economic effects or the restriction of civil rights and civil liberties, as well as other profound ethical and legal issues inherent in various pandemic mitigation approaches being proposed domestically and internationally), a key focus was on the need for ethical guidelines for action in a pandemic, engaging the public in that process,

and maintaining free and open advance planning and communication. Recommendations address some of the most challenging issues in this regard, including shortages of antivirals, vaccines, medical care, and global supply chains, as well as social distancing, duty to care, and the need for enhanced national and global public health capacities, coordination, and planning.

1.1.5.3 Nuffield Council on Bioethics. (2007). *Public health: ethical issues*. Retrieved from: http://www.nuffieldbioethics.org/go/ourwork/publichealth/publication_451.html

This report considers the responsibilities of government, industry, individuals and others in promoting the health of everyone, all while respecting the central value of autonomy. The report suggests that the state has a particular duty to help people lead a healthy life and to reduce inequalities, and advocates for the adoption of a 'stewardship model' for public health policy that outlines how that duty can be discharged and those aims achieved. The stewardship model attempts to balance Mill's *harm principle* (which holds that the only legitimate basis for interfering with a competent individual's autonomous choices is when such decisions might harm others, and is frequently referred to in the public health ethics literature) against Mill's far less frequently cited view that coercion may be justified if and as necessary to ensure that individuals bear their fair share of the communal work needed to secure the interests of society. Stewardship is said to involve adherence to the "intervention ladder", a decision guide that assists in minimizing the restriction of individual liberties, and in avoiding unnecessary paternalism or coercion. The report:

- Considers in significant detail the acceptability of different public health policies and measures that aim to provide and maintain at least some public goods,
- Highlights the responsibilities of industries that promote products that affect health, and
- Argues that state intervention is justified when market failures put population health at significant risk.

Recommendations for policy are made in four areas: Infectious disease, Obesity, Alcohol and tobacco, and Water fluoridation.

The key ethical issue in relation to infectious disease, according to the report, is how to "reconcile consent and civil liberty concerns with community benefit" (Nuffield, 2007, p. 77), and three principles are said to be of key importance when evaluating public health interventions: the harm principle, caring for the vulnerable, and autonomy and consent.

The discussion of infectious disease as an important case study for public health ethics does not focus solely on influenza pandemics or on measures to control such an event. Instead, the focal points include a broad review of the causes and consequences of infectious diseases (including vaccine preventable illness and HIV and other notifiable diseases), a detailed comparison of vaccination strategies and programs, and the importance of surveillance, information sharing, and a more equitable global distribution of public health resources.

1.2 GLOSSARIES

Weed, D. L. & McKeown, R. E. (2001). Ethics in epidemiology and public health I – Technical Terms. *Journal of Epidemiology and Community Health*, 55(12), 855-857. Retrieved from: <http://jech.bmj.com/content/55/12/855> (Free access, but registration required)

The first part of a two-part glossary of terms used in public health ethics. Included here are pertinent foundational concepts in moral philosophy (such as casuistry, communitarian ethics, justice, obligations, and virtues), described in brief, simple definitions that can be used to discuss justifications for choosing one action over another, and to stimulate debate. Despite variations in use across different disciplines, the authors believe people working from a broad range of perspectives will find the definitions to be accessible. The citations also serve as a guide for further reading.

McKeown, R.E. & Weed, D. L. (2002). Ethics in epidemiology and public health II – Applied terms. *Journal of Epidemiology and Community Health*, 56(10), 739-741. Retrieved from: <http://jech.bmj.com/content/56/10/739.full> (Free access, but registration required)

The second part of the two-part glossary of terms used in public health ethics, focusing on terms used in the professional practice of epidemiology and public health. Written to increase sensitivity to ethical issues and skills in ethical analysis, definitions are provided for concepts representing important practical issues with significant ethical content, including advocacy, coercion, equipoise, informed consent, privacy, the precautionary principle, and vulnerable populations.

Krieger, N. (2001). A glossary for social epidemiology. *Journal of Epidemiology and Community Health*, 55(10), 693-700. Retrieved from: <http://jech.bmj.com/content/55/10/693.full> (Free access, but registration required)

“Social epidemiology”, which insists on explicitly investigating social determinants of population distributions of health, disease, and well-being, has developed theories, concepts, and methods conducive to this task. This glossary provides a selection of critical terms for the field, including discrimination, eco-social theory, human rights and social justice, multi-level analysis, social determinants of health, and stress.

1.3 MISCELLANY

Barry, J. M. (2009). *White Paper on Novel H1N1. Prepared for the MIT Center for Engineering Systems Fundamentals*. Massachusetts Institute of Technology. Retrieved from: <http://esd.mit.edu/WPS/2009/esd-wp-2009-07-072709.pdf>

An in-depth but accessibly written review of the emergence of swine flu that provides easy to understand background information on influenza biology and the history of influenza pandemics, along with straightforward discussion of the use and likely effectiveness of pharmaceutical and non-pharmaceutical measures in response to AH1N1.

Paranthaman, K., Conlon, C. P., Parker, C. & McCarthy, N. (2008). Resource Allocation during an Influenza Pandemic. *Emerging Infectious Diseases*, 14(3). Retrieved from: <http://www.cdc.gov/EID/content/14/3/520.htm>

A short but very informative letter to the journal editors on the work that remains to be done in most societies when it comes to making resource allocation decisions, which the authors argue requires the following: 1) making clear societal decisions on the goals for healthcare resources; 2) conducting operational research to develop an evidence base to support the achievement of these goals; and 3) developing systems to capture and learn from new information in a pandemic to facilitate modification of the response as the characteristics of the pandemic emerge.

Simpson, Brian W. (2009). *Prelude to the Fall: Special Flu Report. 5 Lessons about H1N1*. Magazine of the Johns Hopkins Bloomberg School of Public Health. Retrieved from: http://magazine.jhsph.edu/2009/summer/features/special_flu_report/

Virology and vaccine experts share five lessons about AH1N1 as well as their thoughts on what might happen - and what should happen – in preparation.

World Health Organization (WHO) (2009). *WHO supports fair access to influenza A (H1N1) vaccine. An interview with Marie-Paule Kieny*. Bulletin of the WHO, 87(2009). Retrieved from: <http://www.who.int/bulletin/volumes/87/9/09-030909/en/index.html>

A short question and answer session with the director of the Initiative for Vaccine Research at the WHO on how it is supporting countries' efforts to protect their populations with vaccines, despite the complexity involved in the manufacture, distribution, cost, and regulation of such an essential public health tool.

Ritvo P, Wilson K, Gibson J.L. et al. (2010). Canadian survey on pandemic flu preparations. *BMC Public Health* 10(125). Retrieved from: <http://www.biomedcentral.com/1471-2458/10/125>

Key elements of the ethical framework, 'Stand on Guard for Thee: ethical considerations in pandemic influenza preparedness' were transformed into survey form in order to obtain opinions on key ethical issues in pandemic planning. The results it generated when administered to a random sample of 500 Canadians between 2008 and 2009 are presented in this article.

The Ethics During a Pandemic Survey (2008) is available at: http://www.surveymonkey.com/s.aspx?sm=GG_2b8aLzfFRR_2byAz6i_2fAtYA_3d_3d.

2 INTERNET, LEARNING AND DISCUSSION RESOURCES

2.1 PUBLIC HEALTH ETHICS CODES, SUMMARIES, CURRICULA AND NEWS SOURCES

- Population Health Ethics: Annotated Bibliography – Greenwood, H. L. & Edwards, N. (2009).

This document contains key recent foundational readings compiled by the Canadian Institutes of Health Research (CIHR) into three categories: theoretical foundations and principles, frameworks, and case studies.

Available at: <http://www.cihr-irsc.gc.ca/e/40740.html>.

- CIDRAP – Center for Infectious Disease Research and Policy, University of Minnesota. This site is an excellent source for wide-ranging, current, in-depth, and authoritative information on emerging infectious diseases, bioterrorism, influenza, and related topics. New journal articles and original news stories are updated daily, with careful attention given to offering a balance of public health, medical, and public policy perspectives.

Available at: <http://www.cidrap.umn.edu/cidrap/content/influenza/panflu/index.html>.

- CanPREP – Canadian Program of Research on Ethics in a Pandemic. This site is the communication hub (connecting members of the research team, policy makers, health care workers, and members of the public to each other and to ethics resources, including journal articles, media reports, and policy documents) of CanPREP, an interdisciplinary project based at the Joint Centre for Bioethics at the University of Toronto aimed at addressing the ethical challenges that arise in preparing for and responding to a pandemic.

Available at: <http://canprep.ca/index.php>.

- Public Health Ethics – a peer-reviewed quarterly academic journal devoted to the sub-field since 2008.

Combining theoretical and practical concerns from various fields (including philosophy, law, and politics, but also epidemiology and the medical sciences), *Public Health Ethics* provides in-depth analyses of moral issues across the spectrum of public health practice (including epidemiological research, health promotion, infectious diseases control, screening, population genetics, resource allocation, health care system reform, vaccinations, environmental and lifestyle factors relevant to health, equity, justice and global health).

Available at: <http://phe.oxfordjournals.org/>.

- Ethics and Public Health: Model Curriculum – Association of Schools of Public Health (2003).

This project, by the (U.S.) Association of Schools of Public Health, the Health Resources and Services Administration (HRSA), and The Hastings Center, is intended as a resource to enhance and encourage discussions of ethical issues in the field of public health. Each

topical module presents an issue essay, fact sheet, case study, tools for assessment, and a reading list.

Available at: <http://www.asph.org/document.cfm?page=777>.

- Principles of the Ethical Practice of Public Health – Public Health Leadership Society (2002).

Funded by the Centers for Disease Control and Prevention and the Public Health Leadership Society (PHLS), the code highlights the ethical principles that follow from the distinctive characteristics of public health and notably the key belief in the interdependence of people. The code is intended principally for public and other institutions in the United States that have an explicit public health mission, but other institutions and individuals whose work affects the health of the community may also find it relevant and useful.

Available at: <http://www.phls.org/home/section/3-26/>.

2.2 ELECTRONIC NEWSLETTERS & DISTRIBUTION LISTS (LISTSERVS)

- InterPHEN – The International Public Health Ethics Network of the International Association of Bioethics (IAB).

Available at: <http://www.freelists.org/list/interphen>.

- Ethics Newsletter – American Public Health Association (issued quarterly).

Available at: <http://www.apha.org/membersgroups/newsletters/spignewsletters/ethic/>.

2.3 BLOGS & OTHER UPDATES

- Effect Measure

Effect Measure is a forum for public health discussion and argument, as well as a source of public health information from the web.

Available at: <http://scienceblogs.com/effectmeasure/>.

- Pandemic Information News

Pandemic Information News provides a daily chronicle of ongoing events pertaining to infectious diseases.

Available at: <http://pandemicinformationnews.blogspot.com/>.

- Canadian Medicine News

Canadian Medicine News covers health news from coast to coast to coast. It is also host to a database of Canadian physician bloggers, with over 60 doctors' blogs.

Available at: <http://www.canadianmedicineneeds.com/>.

2.4 OTHER PANDEMIC ETHICS RESOURCES

2.4.1 Canada

- Provincial Health Ethics Network (PHEN) of Alberta
PHEN is a non-profit organization which provides resources for addressing ethical issues related to health (PHEN website).
Available at: <http://www.phen.ab.ca/pandemicplanning/guidelines.asp>.
- Canadian Centre for Occupational Health and Safety (CCOHS)
The Pandemic Planning section of the CCOHS's website provides helpful documents and tools. The Links section gives more information on various aspects of pandemics.
Available at: <http://www.ccohs.ca/pandemic/subject/ethics.html>.
- Canadian Medical Association (CMA)
The Ethics and Pandemics section of the CMA's website provides links to resources including a policy statement addressing the ethical issues involved in communicable disease pandemics.
Available at: http://www.cma.ca/index.php/ci_id/53579/la_id/1.htm.

2.4.2 International

- Addressing ethical issues in pandemic influenza planning (WHO)
The project web page for the World Health Organization's (WHO's) Department of Ethics, Equity, Trade and Human Rights includes links to many international reports, consultation summaries, and other resources related to pandemic influenza and ethics.
Available at: http://www.who.int/ethics/influenza_project/en/index.html.
- Ethical Guidelines Documents (Centers for Disease Control and Prevention)
The "Ethical Guidelines" section of the U.S. Centers for Disease Control and Prevention (CDC) website has links to documents that have identified ethical considerations relevant to public health decision-making during planning for and responding to pandemic influenza.
Available at: <http://www.cdc.gov/od/science/integrity/phethics/guidelinesPanFlu.htm>.
- Pandemic Planning (The Hastings Centre)
The *Pandemic Planning* resources provided by this independent, nonpartisan, and nonprofit American bioethics research institution include recent journal articles, letters, and web commentaries. There are also links to other collections, to Hastings Centre experts, and to a useful academic background on resource allocation during a pandemic.
Available at: <http://www.thehastingscenter.org/Issues/Default.aspx?v=256>.

- **Pandemic Influenza: Ethics and Preparedness (Indiana University Center for Bioethics)**
Current only until 2006, this collection of resources is nonetheless notable given the breadth and diversity of links provided, including journal articles, laws, policies, guidelines, training materials, case studies, a conference report, and an ethics toolkit for health care practitioners.
Available at: <http://bioethics.iu.edu/>.
- **Ethics of Pandemic Flu Preparedness (Geisinger)**
General resources, including a Guide and Checklist for individuals and families, as well as readings recommended by the Geisinger Bioethics Review and Advisory Committee on the ethical considerations related to an influenza pandemic.
Available at: <http://www.geisinger.org/professionals/services/bioethics/flu/>.
- **Guide to Recent Studies and Workshops on Pandemic Flu (Institute of Medicine - IOM)**
A summary of the many expert group activities recently organized by the IOM on major policy issues related to pandemic influenza and other infectious disease threats. The guide highlights action and information useful for implementation of pandemic planning and response related to public communication, medical and non-medical prophylaxis, outbreak mitigation, and surveillance, research, and evaluation during a pandemic.
Available at: <http://www.iom.edu/Global/News%20Announcements/IOM-Pandemic-Influenza-Guide.aspx>.

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