

Conference Report

Disease, Disaster, and Democracy: The Public's Stake in Health Emergency Planning

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ON MAY 23, 2006, the Center for Biosecurity of the University of Pittsburgh Medical Center convened an invitational U.S.-Canada summit in Washington, DC, on *Disease, Disaster, and Democracy*. The conference was held in collaboration with the Canadian Policy Research Networks (CPRN), the Center for Science Technology and Security Policy of the American Association for the Advancement of Science, and the National Consortium for the Study of Terrorism and Responses to Terrorism (START), a U.S. Department of Homeland Security University Center of Excellence.

The 200 people in attendance included community activists, humanitarian relief workers, volunteer organizers, medical and public health professionals, emergency managers, academics, congressional staff, and government officials from virtually all of the U.S. federal agencies. Among the attendees were people with direct experience in the spectrum of modern disasters, including Hurricane Katrina, SARS, the 9/11 terrorist attacks, and the 1989 Loma Prieta earthquake.

The purpose of the conference was to advise leaders in government, public health, and disaster management on the feasibility and benefits of actively engaging citizens and communities in planning for large-scale health emergencies in anticipation of (1) the ethical dilemmas posed by a scarcity of life-saving medical resources, and (2) the logistical difficulties of protecting the well and caring for the sick in large numbers. A severe pandemic of in-

fluenza served as the hypothetical case with which to test the value of this collaborative problem-solving model in relation to a health disaster.

BACKGROUND

Modern society's ability to handle potentially catastrophic events hinges on the integrity of contingency planning, as well as the foresight to prevent and mitigate devastation. Regrettably, human tragedies associated with Hurricane Katrina have called into question people's collective resolve—both in and out of government—to take care of one another. Public trust in disaster policies is far from certain, particularly among marginalized groups whose needs often go unmet. Independent of whether public policy for disasters or outbreaks is adequate or not, however, is the fact that human societies will continuously face hazards that threaten major loss of life and livelihoods.

Thus, summit organizers conceived of a public event that would promote a cross-border dialogue about the role of individual citizens and civil society institutions alongside that of private enterprise, response professionals, and government agencies in preparing for, responding to, and recovering from an extreme health event. Event planners reasoned that citizen engagement prior to and during a health disaster is one important guarantee

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that emergency plans and their implementation reflect the realities of the people they intend to protect *and* command their confidence.

SYNOPSIS OF TALKS AND ROUNDTABLES

Full transcripts and presentations (where available) are posted at <http://www.upmc-biosecurity.org>. Report authors' synopses of summit proceedings follow below.

Keynote: Why the Public's Trust and Help Matter in Health Emergencies

Both the prospect of large-scale disease outbreaks and the need for the larger public to help remedy these crises are foreign concepts in the present-day U.S., argued Dr. D. A. Henderson, an internationally recognized public health leader and former head of the World Health Organization's campaign to eradicate smallpox.

A severe influenza pandemic, however, could catch the country flat-footed as a result of such thinking when a tidal wave of patients overwhelms the healthcare and public health systems. Given the rate of illness that would be expected among the medical community itself, who will care for all of the patients? Volunteer groups with fundamental training in some medical procedures will be needed, as will people to help with other needs such as delivering critical supplies and manning phone banks.

In comparison with the rest of the world, North Americans over the past century have had only limited experience with epidemic disease and even less experience implementing health programs with limited resources.

Volunteers, in contrast, have been essential to international efforts to combat infectious disease (see Figure 1). Smallpox eradication is a prime example. The success of large-scale vaccination efforts in Africa and South America depended on the advice of village headmen, religious leaders, and school principals and on the manpower of local people who became trained vaccinators.

Panel I—What Government Gains by Engaging the Public

Mary Pat MacKinnon, Director of CPRN's Public Involvement Network, opened the panel by defining citizen engagement, describing its role in democratic governance, and identifying hurdles to implementation. Karen Marsh, Citizen Corps program director for the U.S. Department of Homeland Security, and Éleine Chatigny, Director General for Communications within the Public Health Agency of Canada, then described how homeland security and health officials have involved the public in their missions.

What Does "Public Involvement" Mean?

Citizen engagement, explained Ms. MacKinnon, is a form of deliberative democracy intended to improve representative democracy, not overthrow or replace it. It constitutes an iterative and interactive process among and between citizens and government with the explicit purpose of improving public policy decisions and their implementation.

The American Political Science Association argues that citizen engagement is essential to democratic society because: (1) it provides evidence of citizen preferences to decision makers, (2) it creates legitimacy for public policies, (3) citizens' skills and knowledge are developed

FIGURE 1. NOTEWORTHY FACTS ON THE PUBLIC'S CONTRIBUTIONS IN DISASTERS AND HEALTH CRISES

- The Harris County (Texas) Citizens Corps helped manage 60,000 volunteers in setting up a "mini-city" at the Houston Astrodome to host 65,000 Katrina evacuees.
- Federal health authorities in the U.S. and Canada are reaching out to citizens-at-large for advice on the best strategy to distribute scarce medical resources like antivirals and vaccine in a flu pandemic, accounting for the scientific facts and social values at stake.
- A citizen-led group coupled with a federally supported community disaster mitigation program (Project Impact) transformed flood-prone Tulsa, Oklahoma (9 federally declared disasters from 1970 to 1985), into a model of floodplain management.
- The Junior Chamber of Commerce carried out Sabin on Sunday, a mass vaccination program in cooperation with health departments that reached 80–90% of the target population—a critical step in eliminating polio in the U.S.
- Voluntary groups such as Rotary International are the engine for National Immunization Days around the globe. On a single day, volunteers in Brazil vaccinated nearly all children under 5 years old against polio.
- The March of Dimes, by collecting small amounts from many Americans to support polio vaccine R&D, raised hundreds of millions of dollars which, at the time, amounted to more than all U.S. charities combined, not including the Red Cross.

FIGURE 2. PUBLIC INVOLVEMENT SPECTRUM

Inform or Educate: Perform one-way communications from officials to citizens
Gather Information: Listen and glean people's opinions through polls
Discuss: Hold a public exchange or dialogue about issues
Engage: Foster mutual understanding of complex dimensions of an issue
Partner: Work together to conceive and implement solutions

through direct participation, and (4) civically engaged citizens can provide services that neither the state nor the market can.

Resistance to change and skepticism on the part of both citizens and government can impede the adoption of engagement principles and practices, as can low civic literacy and limited resources. Prerequisites for successful community engagement include clarity of purpose, opportunities for learning, inclusive participatory processes, adequate resources, realistic timeframes, and feedback and evaluation built in at the outset.

A National Charter for Hometown Security

Citizen Corps, Ms. Marsh recounted, was launched by President Bush in his 2002 State of the Union Address as a grassroots effort to make the country safer in the face of natural, technological, and terrorist-driven hazards. The program's infrastructure consists primarily of city- and county-level "councils" that self-organize according to their respective populations, geography, and hazards.

Citizen Corps Councils—whose members typically include government officials, first responders, and civic leaders—are a mechanism to conduct local strategic planning, raise community awareness, and involve people in training exercises and volunteer programs. These include the Fire Corps, Volunteers in Police Service, Neighborhood Watch, Community Emergency Response Teams (CERT), and the Medical Reserve Corps.

The program faces some basic challenges. The Citizen Corps vision will require a cultural shift: first, to break the paternalistic perspective of the government and gain more input on preparedness priorities from people such as civic leaders, private sector executives, and faith-based leaders; and second, to instill a generalized sense of responsibility in the U.S. populace to become informed and involved. Decreasing funding has created an uncertain future for the Corps.

Citizen Engagement at the Public Health Agency of Canada

Public involvement has been a priority objective of the Public Health Agency of Canada (PHAC), explained Ms. Chatigny, since its creation in September 2004 as a result of SARS and renewed attention to the public health sector. Similar in structure to the U.S. Department of Health

and Human Services, PHAC is responsible for health prevention promotion, disease surveillance, and emergency management response and planning. PHAC is committed to reversing the trend in which authorities excel at one-way communications but are less well versed in the other end of the "public involvement" spectrum (see Figure 2).

The Communications Directorate includes a "risk communications and public involvement" unit, building on prior Health Canada commitments to create opportunities for health officials and citizens to interact and produce better policy. PHAC has relied on roundtable conversations, web surveys, and other communication techniques to garner input on public health goals and priorities from different levels of government and diverse citizen groups including First Nations peoples. PHAC also has adopted an ethical framework to help guide pandemic planning and is piloting a citizen engagement application to garner input on the prioritized use of scarce antivirals.

Panel II—Show Me! An Inside Look at Citizen Engagement

The second panel—moderated by Denise Gray-Felder, President and CEO of the Communication for Social Change Consortium—spotlighted three exemplary citizen engagement programs in the realm of disaster and public health preparedness.

Grassroots Hazards Management in Tornado Alley

Despite ever-present flood and tornado threats, Tulsa, Oklahoma, has become a safer, more prosperous community through grassroots-government collaborations, argued Ann Patton, the founding director of Tulsa Partners, Inc., and former director of Tulsa's Project Impact and Citizen Corps Council.

Fed up with repeated flooding, a local housewife named Carol Williams organized "Tulsans for Better Community," tapping into the widespread frustration and loss associated with flood disasters from 1970 to 1985. This citizen-led effort received a boost when Tulsa became a Project Impact (PI) community in 1998. FEMA funded PI grassroots mitigation programs in 250 communities from 1997 to 2001. The city continued to fund dis-

aster mitigation efforts even after the federal program was discontinued. Citizens Corps and Tulsa Partners, Inc., perpetuate the vision of “ordinary citizens working together for safer lives and better communities.”

Homegrown and federal efforts helped raise local consciousness about disaster mitigation; concrete benefits included (1) residents’ embrace of bond issues and new sales taxes in the interest of better floodplain management, and (2) improved relations between consumers and the Tulsa Home Builders Association with the construction of tornado-safe rooms in thousands of new residences.

A Bayou Community’s Cultural and Physical Survival

Residents of Grand Bayou, Louisiana, who had been buffeted by recurrent hurricanes and storm surges, similarly organized themselves for disaster mitigation and sustainable development aims. Grand Bayou is home to a Native American and Cajun ocean-farming community that has persisted for several hundred years, weathering coastal hazards through keen understanding of the local environment and strong social bonds. Increasingly powerful hurricanes, such as Lili and Isador in 2002 and Katrina and Rita in 2005, coupled with ecological changes wrought by the region’s oil and gas industry and agricultural improvements, have threatened their cultural and physical survival.

In response, local residents formed the nonprofit Grand Bayou Families United to assure their community’s future, partnering with state and local government, business, the faith community, and university experts in environmental science, disaster management, and social and behavioral science. (The presenter, Reverend Kristina Peterson, is a founding member of the group.) The Grand Bayou residents have augmented authorities’ understanding of the larger environmental transformations and worked within their community to devise better ways to cope with coastal dangers. This self-reliance strategy proved necessary in the wake of Katrina and Rita, when the community lost more than 60 square miles of land and did not receive sufficient outside rescue/assistance.

The Public’s Take on “Who’s First in Line for Pandemic Flu Vaccine?”

The Public Engagement Pilot Project on Pandemic Influenza (PEPPPI) provided “proof of principle” that citizen engagement on a scientifically complex health issue is both possible and beneficial to national decision makers, recounted Dr. Roger Bernier, Senior Advisor for Scientific Strategy and Innovation at the CDC’s National Center for Immunization and Respiratory Disease. In 2005, a series of experimental public dialogues took place on how best to use the limited doses of vaccine

available in the early phases of an influenza pandemic. Stakeholders from the health sector, federal and state agencies, industry, consumer advocacy groups, and minority groups took part in a national meeting, while citizens-at-large participated in a number of regional meetings.

The goal of these deliberations was to articulate a pandemic flu vaccination program that incorporated both sound technical judgment and broadly held social values. Citizen and stakeholder groups ultimately put forth a distribution strategy with the following priorities: first, assure the functioning of society, and second, reduce individual deaths and hospitalizations due to influenza. In contrast, current federal guidelines devised by a health expert panel put the two priorities in reverse order. A final report on PEPPPI was issued and presented to HHS; in its pandemic flu plans, the agency subsequently acknowledged the need to do further outreach and engage the public.

Lunch Address: Polio as the People’s Disease

Dr. David Oshinsky, author of the Pulitzer Prize-winning book, *Polio: An American Story*, discussed the social history of polio in the U.S., exploring the lasting impact of the popular March of Dimes campaign on both philanthropy and R&D.

Polio outbreaks became common in the U.S. in the 1930s and 1940s, just as penicillin’s introduction catalyzed calls for the eradication of all infectious disease. Polio was perceived as a “crack in the middle-class window,” given the lack of a cure or strategies to protect children and limit infection. Although the virus paralyzed only a small number, the severity of consequences among these patients made polio “a very visual disease.” In response, a popular movement emerged through the March of Dimes, which Franklin Delano Roosevelt, a polio survivor, helped found. The organization introduced innovative concepts of Madison Avenue-style public relations campaigns, celebrity advocates, and mothers’ marches to support polio victims and vaccine research.

Turning philanthropy on its head, the organization sought small donations from millions of Americans rather than contributions from a few wealthy individuals. The hundreds of millions of dollars raised supported a network of basic researchers whose work led to the successful Salk and Sabin vaccines. Positive results from a 1954 double-blind clinical trial of the Salk vaccine in 2 million children—implemented largely by volunteers—were received “as if a war had ended.” The foundation of this collective sense of accomplishment was the “millions upon millions of Americans who gave their time, their money and their children to this cause.”

Roundtable Discussions: Why We Need Citizen and Community Engagement to Get Through the Next Pandemic Flu

Dr. Eric Toner, Senior Associate with the Center for Biosecurity and a clinician with emergency medicine and disaster preparedness experience, set the stage for the afternoon by relaying epidemiologic predictions about pandemic flu today and how medical and public health interventions might influence outcomes. With this background, roundtable participants debated the merits of enlisting the public's help with two exemplar problems in a severe pandemic: (1) the ethically defensible use of scarce, life-saving medical resources such as vaccines, antivirals, antibiotics, and hospital beds; (2) the complex logistical challenge of caring for many sick people when hospitals are beyond their functional capacity.

What Would a Modern-Day Flu Pandemic Look Like?

No one can predict with certainty exactly how a modern-day influenza pandemic will manifest itself, Dr. Toner noted. The 1918, 1957, and 1968 experiences suggest, however, that pandemics happen quickly and affect many communities simultaneously. In 1957, it took only 2 months for the outbreak to become nationwide.

Based on the HHS planning assumption of a 1918-like pandemic and CDC's *FluSurge* software, local hospitals today can expect to have only 1 mechanical respirator for every 2 flu patients, and only 1 bed for every 4–5 flu patients who need them at the peak of the crisis. Because hospital surge capacity is limited, it is unrealistic for a community to expect that flu patients would receive normal standards of care and that other healthcare services would be unaffected.

The following public health interventions, argued Toner, cannot halt a novel flu virus. At best, they may slow the spread of disease, although this is not yet proven:

- **Vaccines:** Because the flu virus is constantly changing, vaccine developers cannot predict the pandemic strain. Consequently, vaccine cannot be made or stockpiled in advance. Limited manufacturing capacity and antiquated technology also mean that vaccine will be available slowly and incrementally. Once produced, the efficacy of a new vaccine is never certain.
- **Antivirals:** Limited supply and production capacity mean that widespread prophylaxis is not practical. Also, viral resistance may develop, the dosage and duration of treatment may vary from strain to strain, and effective treatment will depend on timely administration of the drug.
- **Disease containment:** Measures include isolating the sick, identifying/quarantining those exposed, restrict-

ing travel, closing schools, avoiding crowds, practicing respiratory etiquette, washing hands, and using protective masks. Some features of flu make it hard to contain through these methods, however. A 2-day incubation period leaves no time to trace contacts or implement quarantine. A very short time between generations (2–3 days) means that flu spreads rapidly, making geographic controls impractical. Some degree of asymptomatic spread may prove isolation only partially effective.

Who Receives the Limited Doses of Pandemic Flu Vaccine?

Dr. Peter Singer, director of the University of Toronto Joint Centre for Bioethics, led the participants listed below in a role-playing exercise in which health officials receive only a portion of the flu vaccine needed to cover priority groups. They along with elected officials face the dilemma of deciding who is last in line to receive the vaccine—and then having to explain that decision. Reflecting on the scenario, participants considered the value of involving the public early in decision making about the proper use of scarce vaccine.

- Maggie Fox, Health and Science Correspondent, Reuters
- Peter B. Gudaitis, MDiv, Executive Director & CEO, New York Disaster Interfaith Services
- Dan Hanfling, MD, Director, Emergency Manager and Disaster Medicine, Inova Health System, Falls Church, Virginia
- Carol Jordan, RN, MPH, Director of Communicable Disease and Epidemiology, Montgomery County Department of Health and Human Services (Maryland)
- Sarah Landry, MS, Director, Public Policy for Vaccines, GlaxoSmithKline; former Associate Director of Policy and Program Operations, National Vaccine Program Office, DHHS
- Nelson Ortega, Executive Director, Centro de la Comunidad, Baltimore, Maryland

Some major themes that arose in the discussion:

- **Many ethical considerations remain unresolved.** Despite a national committee's efforts to develop guidelines for vaccine distribution, many ethical questions remain unconsidered and problematic. Questions about the "value of life" persist: children are not currently considered priority vaccines, while the elderly are afforded greater importance. Cultural and faith traditions may "rank" categories of people differently, and definitions of "critical personnel" depend on local conditions. Transit workers, for example, undergird New York City's livelihood.

- **Pre-event plans and priorities may not match the requirements of a real pandemic.** No one can predict with certainty how an actual pandemic flu will affect different populations, nor how well a vaccine may work in an actual crisis. Prioritization frameworks derived prior to the real event may prove irrelevant or in need of significant revision. Thoughtful prioritization frameworks do not alter the underlying problem of no vaccine, ineffective vaccine, or vaccine that is late in coming.
- **Public discussions about priorities and uncertainties, as well as pre-planning, are still warranted.** Public acceptance of preliminary and/or evolving plans about prioritized access to vaccine will require engagement and dialogue. Involving the public early in the scarcity discussion may help set realistic expectations about vaccine availability, in addition to soliciting citizen input on prioritization strategies.
- **Alternatives to care should be presented to the public.** Citizens who are unlikely to receive initial doses of vaccine—and the public more broadly—deserve meaningful information about self-protection and self-care. Such guidance can help assure people that they and their families are not helpless in the absence of vaccine.
- **Policies about pandemic flu vaccine production and distribution have an international dimension.** Some participants questioned whether it was feasible for the U.S. to produce vaccine without providing a portion to countries where outbreaks arise or to nations who are unable to produce their own vaccine.

What if Hospitals Cannot Take Everyone In?

Dr. Tara O'Toole, Director of the UPMC Center for Biosecurity, moderated a role-playing exercise to reveal how hospital staff, local officials, and affected residents might react to an overwhelming surge of flu patients during a severe pandemic. Conversation among the participants (listed below) shifted then to identifying steps that can be taken now toward sustainable communitywide plans and vibrant volunteer networks to help deliver care for flu victims and maintain other essential medical services in the community.

- Ann Beauchesne, Executive Director, Homeland Security Division, U.S. Chamber of Commerce
- Arrietta Chakos, Assistant City Manager, City of Berkeley, California
- Christa-Marie Singleton, MD, MPH, Chief Medical Director, Baltimore City Health Department's Office of Public Health Preparedness and Response
- Jan Lane, Deputy Director, George Washington University Homeland Security Policy Institute; former

Vice President of Public Policy and Strategic Partnerships, American Red Cross

- Diane Lapson, President, Independence Plaza North Tenant Association, Manhattan, New York
- Robert Tosatto, RPh, MPH, Commander, U.S. Public Health Service; Director, Medical Reserve Corps
- Richard Waldhorn, MD, Distinguished Scholar, Center for Biosecurity of UPMC; former Physician-in-Chief, Georgetown University Hospital

Key themes that emerged during the exercise and subsequent discussion:

- **Hospitals on their own cannot handle the medical demands of a severe pandemic.** Hospitals will not be able to operate effectively in the face of labor shortages that result from workers falling ill, having to care for sick family, and/or being concerned about bringing home contagion. Hospitals may run out of even basic supplies due to patient demand and/or interrupted delivery chains. Routine care will likely suffer, and emergency rooms risk becoming amplifiers of disease as more people crowd the hospitals.
- **Citizen volunteers are invaluable during a major health crisis.** Volunteers can relieve hospitals by establishing phone banks to answer calls from concerned citizens and caring for children of critically needed staff. They also can help organize and staff alternative care facilities and serve as a support network for the homebound sick and their families. Involving people can decrease fear and enhance a sense of control in chaotic times.
- **Denial of hospital care can become a reality.** Decisions concerning triage need to be debated and laid out publicly, as well as distributed to doctors ahead of time; these decisions are too complex and important to be made during a crisis. This discussion paralleled the prior roundtable's focus on the need for public deliberation of the tough ethical decisions related to scarce medical resources.
- **Local officials will be the primary decision makers.** Few requests for aid were made to the role-playing federal official, suggesting that most crisis-related decisions will be left to local leaders. In addition to decisions regarding hospital care, public health officials and mayors must be prepared to make coordinated public announcements regarding school closings, locations of additional acute care facilities, and availability of information hotlines.
- **Communitywide pre-planning is essential.** Communities can handle a pandemic more effectively and humanely if government, the health sector, businesses, NGOs, and community groups actively collaborate in

pre-planning and response exercises, and if citizens assume a larger role in pandemic preparedness. Untapped are the logistical and managerial potential of the private sector as well as the on-the-ground capabilities of neighborhood associations and CERTs. The federal government can play a significant role in building up local readiness.

NEXT STEPS

The Center for Biosecurity of UPMC is presently convening a Working Group on Citizen Engagement in

Health Emergency Planning to follow up summit issues in greater detail and, by the end of the year, will release “best principles and practices” guidance for elected officials, health authorities, and emergency managers.

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