

Citizen response to pandemics, authorities' nightmare or daydream?

On the need of relying on citizen and community engagement during pandemics

Ira Helsloot, Professor of Crisis Management and the Politics of Safety, Faculty of Social Sciences, Vrije Universiteit Amsterdam, i.helsloot@fsw.vu.nl

Sandra Crouse Quinn, Associate Professor, Department of Behavioral and Community Health Sciences, Graduate School of Public Health, University of Pittsburgh, squinn@pitt.edu

Paper prepared for the 2009 American Political Science Conference, Toronto, September 3-6

Abstract

The challenges that a pandemic outbreak poses are beyond the organizational capabilities of the authorities of any given state. The handling of such an outbreak calls for close collaboration with numerous private actors but most of all with citizens. Pandemic outbreaks are unique in this feature in the sense that the control of almost no other crisis is so dependent on the rational complying citizen. This clearly has important meaning for the preparation on large scale outbreaks. However, in practice, 'the plan' does not account for this crucial citizen aspect. On the contrary, planning for pandemics usually only mentions the risks panicking poses. This paper will examine the necessity for community participation in preparing for and responding to pandemics in practice and in theory. The political constraints on deciding for community participation are analyzed.

*“It really is all of humanity that is under threat during a pandemic.” Margaret Chan,
Director General of the World Health Organization, May 9, 2009*

1. Introduction

Governments throughout the world grapple with threats to the public’s health such as climate change and its devastating impact on displacement, mitigation and environment, enormous natural disasters such as the 2004 Indian Ocean tsunami, and the global pandemic of HIV/AIDS. New threats continually emerge that demand novel strategies to prepare our citizens and communities. For much of the past decade, the WHO and governments around the world have been concerned about the threat posed by an avian influenza, H5N1, which has a high case fatality rate but fortunately, has not yet become easily transmissible between humans. Then, in April 2009, reports of a new swine influenza, later identified as H1N1, a strain totally new to humans, emerged from Mexico. By August, 2009, the World Health Organization (WHO) reported that “177 countries have officially reported 182,166 confirmed cases of influenza A(H1N1) infection, including 1,799 deaths” (http://www.who.int/csr/don/2009_08_21/en/index.html). In June, the WHO raises its pandemic alert level to the highest level of 6. In fall 2009, countries across the globe will begin vaccination for the novel influenza. Some speculate that the pandemic could resemble the 1957 pandemic, and ongoing uncertainty complicates governmental preparations and communication with citizens.

During the decade, there has been limited movement toward citizen engagement as a strategy to prepare communities and countries for the difficult policy dilemmas and potential social and economic challenges that a pandemic can bring. This occurs despite the fact that the international community formally recognized the critical role of citizen participation in the *Hyogo Framework for Action 2005-2015: Building the Resilience of Nations and Communities to Disasters*, which calls for governments to:

Promote community participation in disaster risk reduction through the adoption of specific policies, the promotion of networking, the strategic management of volunteer resources, the attribution of roles and responsibilities, and the delegation and provision of the necessary authority

and resources (United Nations Inter-Agency Secretariat of the International Strategy for Disaster Reduction, 2005, p.7).

This call echoes that of the Jakarta Declaration on Leading Health Promotion into the 21st Century that calls for partnerships between all sectors of society, increasing community capacity, and enhancing social responsibility for health promotion. However, to date, many of the calls for citizen engagement in pandemic planning have focused on the difficult public policy questions of allocation of scarce vaccines and anti-viral medications, hospital beds and respirators. Although that rationale for citizen engagement is compelling, the efforts to engage citizens in a sustained manner have been limited. Yet the challenges that a pandemic outbreak poses are beyond the organizational capabilities of the authorities of any given state. The handling of such an outbreak calls for close collaboration with numerous private actors but most of all with citizens. This paper will begin with sketching the challenges a pandemic brings with it, the rationale for citizen engagement, barriers to such engagement, how it has been utilized in several circumstances, and its limitations. Then, we expand beyond the policy focus of citizen engagement to an emphasis on community engagement in building resilient societies with the capacity to manage the challenges of a pandemic. We will give recommendations based on our insights on how to handle the current H1N1 pandemic.

2. The outbreak of a contagious and deadly infectious disease: consequences and necessary measures

In this paragraph, we will take a look at the theoretical effects of a global outbreak of a deadly disease. We will describe these effects from the perspective of a given state X. Please note that the phases we use in this paragraph have no relation to those used by the WHO.

Phase 1: an outbreak somewhere in the world

Somewhere an outbreak occurs, which appears to be deadly. It is uncertain whether the affected country manages to control the outbreak. The first question will be whether state X needs to update its preparation level. An obvious preventive question which will be whether something can be done to stop the disease from spreading to the state X. Due to normal international transport of passengers in combination with an incubation time of the infectious diseases, chances are very high that the disease will arrive in state X as well. Measures will be taken to diagnose infected people quickly and contain any people who are infected. The fear of infectious disease could already lead to a global crisis of international

transport compared to 9-11 or SARS. The government will therefore anticipate economic measures.

A rather predictable consequence of the fear of an infectious disease is a flood of worried citizens with symptoms of the disease, which are close to the real symptoms, thus congesting medical services. With the SARS case, there were in the Netherlands and the United Kingdom for every 100 “false” disease suspicions, only one real case that needed further scrutiny.

One dilemma, about which authorities ponder, is the question whether public preparations for disease management will lead to increasing fear amongst the public. Research suggests that ‘earning public confidence’ is an important part in managing fear. Consequential, daily information should therefore come from the government, but it remains open to questions as to what the government should precisely provide and through which channels.

Phase 2: A few infected people in state X

A few people are diagnosed with the contagious infectious disease in state X.

It is very likely that large social unrest (no panic!) will be caused by the spreading of the disease to state X. Although the almost inevitable first case of this deadly virus is not an indication of ‘failing’ preventative measures, it will be argued that further restrictions of those measures are necessary. The public pressure to adopt stronger preventative measures and to prepare for operational measures will be tremendous.

People will try to avoid busy public locations because of fear of contamination. This is an efficient “self protection measure,” which will prevent further spreading of the disease somewhat. Public transport and other public services will be used less, and therefore, the economy will most likely suffer. People will specifically be inclined to leave the places where the first infected were found. Health services will be struggling with the number of people who think they have the symptoms of the infectious disease.

Phase 3: Several dozens of infected people in state X

There now are several dozens of infected people in state X.

The focus of preventative measures will now switch from international to national preventative measures: the question will be how to contain any infections inside state X. The

public pressure to close, for example, schools near infected cities or towns will be very large. Especially local authorities will be troubled by this.

Dozens of infected people are more than ‘regular’ emergency services can handle. Emergency measures (like setting up emergency isolation facilities) will be required. Buildings and hospitals will need to be adjusted on a limited scale, but chances are that hospitals will not have too much space and that therefore buildings will need to be “confiscated”. The problem of choosing locations for the emergency facilities are very high, authorities will conclude that you can’t just put infected people in their own houses (i.e. quarantine), because public unrest near those houses will be high. Houses are also difficult in terms of security.

Because of fear of contamination, the citizens of state X will avoid public places altogether and withdraw in to their own surrounding. The social and economic life will suffer severely. The already troubled health services will have more and more problems.

In this phase, the disruption of state X’s society will be so large, that national crisis management becomes necessary. Emergency state law will be required and in the infected municipalities, policy teams and action centres will become active. In this phase, three dilemmas will arise which are predictable in nature, but for which no solution has been found yet:

- When a local area is infected, it is quite logical and common that people will want to leave that place. Yet containing a disease is only manageable if possibly infected people remain where they are, as soon as they mingle with other people chances are that the disease will spread. Right now there are no legal instruments requiring people to remain in the same place.
- Special risks are homeless and illegal (in the larger cities) people who cannot easily be controlled.
- Protection of health workers and security related personnel will need to be guaranteed.

Phase 4: the worst case: massive contamination in state X

In state X, an outbreak occurs that infects thousands of people.

In this ‘worst-case’ scenario, it is immediately clear that medical services will be overcrowded. Prioritising will be required within the medical sector; concretely this will also mean that hospitals require increased security.

It appears also to be inevitable that a large proportion of the national workforce will no longer want to perform their work, because of fear for infection. Daily life will most likely halt. Public transport will not function anymore and other public services will large be vacant.

It will be immediately clear that the national government has the final responsibility for the crisis. Integral disaster management will be required, which finds its legal basis in state emergency management. A national curfew may be required.

3. Current Rationales for Citizen Engagement

Pandemics, by definition, take their toll on communities and governments over time, across borders, and affect every aspect of society. How can citizen engagement strengthen our societal ability to withstand the effects of a pandemic? The rationale for such engagement, which has been clearly articulated by numerous authors and can clearly be found in our sketch of the effects of a pandemic outbreak above, rests on multiple arguments and assumptions:

- 1) In a pandemic, the demand for anti-viral medications, vaccines, hospital beds, and other resources will exceed the supply;
- 2) The ethical dilemmas posed by these shortages and related policy decisions must be informed by public participation and societal values;
- 3) We need the public to be engaged in reducing their own risk of disease and caring for themselves and others;
- 4) The demand for services to maintain society will outstrip government's capacity and requires community based organizations, civil society, private sector, and others to work collaboratively and ensure that our civic infrastructure be sufficient to weather the challenges;
- 5) It will be essential to supplement official responders, from health care professionals to others, with volunteers; and
- 6) Finally, greater citizen engagement will foster greater capacity to manage the pandemic and emerge as a resilient society (National Research Council, 2006) (Schoch-Spana M. C., 2006) (Quinn, 2008) (The Working Group on "Governance Dilemmas" in Bioterrorism Response, 2004). (Schoch-Spana, 2008) (Schoch-Spana et al, 2007).

<p>The SARS epidemic highlighted an acute shortage of epidemiologists and other essential public health professionals. In Toronto, it took an average of over nine hours per case to perform contact tracing, and there were 2,282 cases to investigate. Bringing in staff from other</p>

jurisdictions was not a solution because knowledge of local conditions was essential in contact tracing. Owing to the strain of SARS on local resources, WHO played a crucial role in several countries. Further, while epidemics always place burdens on health care providers, SARS, by infecting health care workers at a high rate, presented enormous challenges. The immediate one was maintaining adequate staffing levels during outbreaks. Not only were health care workers incapacitated due to illness or quarantine, in every country we studied, physicians and nurses avoided caring for infected patients, and officials responded with penalties and/or incentives. Long-term repercussions for health care staffing follow from reports of psychological problems (e.g., exaggerated and disabling fear of infectious disease) and, as in Toronto, departures from the health professions and declining enrollment in training programs.¹

There has been less emphasis on another critical argument for citizen engagement. Building trust between citizens and government is essential, particularly for minority and immigrant populations whose relationships with official government may be problematic. In her instructive essay on two smallpox outbreaks, Leavitt describes a historical example of the tragic impact when the actions of the Health Officer for Milwaukee were perceived by immigrant communities as discriminatory, and the resulting social disorder and unnecessary toll from the disease (Leavitt, 2003). We know from more contemporary events in the US, such as Hurricane Katrina and the 2001 anthrax attack, that African Americans do not see communication from government sources as trustworthy and fair (Quinn, 2008). More recently, in Cairo, the Egyptian government's decision to cull all pigs as a means to reduce the risk of H1N1 was seen by their Christian owners as a discriminatory act that was not justified by the public health science. The conflagration of religion, poverty and discrimination, embodied in what was officially described as a public health tool, created further alienation of an already marginalized group (Slackman, 2009) (Audi, 2009). Clearly, the Working Group on "Governance Dilemmas" in Bioterrorism Response was correct when they called attention to one of the challenges in the context of emergency events: "Conditions that confound social trust involve preconceptions about the government, the public or the media, social and economic fault lines that are exacerbated by disease or the dread of it..." (The Working Group on "Governance Dilemmas" in Bioterrorism Response,

¹ *Quarantine and isolation: lessons learned from SARS; A Report to the Centers for Disease Control and Prevention*, Institute for Bioethics, Health Policy and Law, University of Louisville School of Medicine, M. A. Rothstein, et al.

2004, p.30). The extent to which citizen engagement, when it is truly inclusive, can generate trust or heal breaches is unknown, yet seems promising.

Cameron reminds us that “Every pandemic is the sum of local epidemics, and every city and village has its own story. Mega-cities will have ‘mega-demics’ through crowding, poverty, mobility and mixing of so many people as the natural world has never seen before” (Cameron, 2007, p.3). That places particular stress on governments to fully engage people who are typically marginalized within their societies including minority and immigrant populations, many of whom are the most vulnerable in our societies. To do so, we must be cognizant of the importance of language describing these processes. Although many authors use the term, citizen engagement, we will use community engagement. This is purposeful. Citizen engagement may be exclusionary for those immigrant populations who may indeed be particularly vulnerable in a pandemic and yet are not official citizens of the country in which they reside. In the SARS epidemic, we saw instances of stigmatization and discrimination against Chinese residents in the US. In the pandemic, its origins in Mexico have subjected Mexican immigrants, particularly those who are undocumented, to further stigma in the US and visitors from Mexico to more repressive actions in China. In this context, this shift in language, while seemingly minor, may be essential in many countries throughout the world in which immigrant populations, particularly those who differ racially and socio-economically, may be more vulnerable and at the same time, more likely to be left out of the policy and planning discussions.

4. Barriers to Community Engagement

While the rationale for community engagement in pandemic planning and response may be convincing, the ambivalence of governments about community engagement for pandemic planning has played out over the past several years in the US. In 2006, then President Bush signed the Pandemic and All Hazards Preparedness Act of 2006, which created cooperative agreements that mandated the development of public health preparedness plans, and required “a description of the means by which to obtain public comment and input on the plan and on the implementation of such plan, that shall include an advisory committee or other similar mechanism for obtaining comment from the public and from other State, local, and tribal stakeholders...”

In 2007, Homeland Security Presidential Directive 21, National Strategy for Public Health and Medical Preparedness (HSPD-21) identified community resilience as one of 4 critical components of preparedness. However, Schoch-Spana and colleagues (Schoch-

Spana, 2009) assert that federal funds necessary to implement the type of community engagement activities have not been available to enable government to move forward. With unfunded mandates, public health agencies and local/state governments are unlikely to have the human or fiscal resources to allocate to the intensive efforts needed for community engagement. To remedy this situation, Schoch-Spana and colleagues advocate that the new Obama administration take explicit action to support the following:

1. Work with Congress to provide additional funds to enable state and local health agencies to increase public engagement to build partnerships with grassroots groups and enable public to participate in policy decisions; and
2. Encourage the Centers for Disease Control and Prevention to identify community engagement as a priority in their Public Health Emergency Preparedness grant funding; engage those local and state health departments with strong capability in community engagement to provide technical assistance to other health departments; identify community resilience partnerships as a funded activity in the, and determine as priorities for such funding the non-profits “rooted in and representative of minority communities where social networks, cultural practices and special needs are not well understood by mainstream organizations” (Schoch-Spana, 2009, p.2).

However, lack of resources is clearly not the only barrier to adopting community engagement in pandemic planning. Certainly, one common assumption of government, heard frequently in the media during any crisis, is that the public will either panic, be passive or start looting (for a review of the literature on this theme, see Helsloot 2004). We will address the findings on these three myths of citizen behaviour during disasters below. Especially the first myth is ever present amongst authorities.

Myth 1: Citizens panic during a disaster

The initial “reaction of fright” of citizens in emergency situations quickly changes in the search for possible security of himself or other citizens. Bystanders and ordinary citizens usually provide help during disasters, especially in the early hours of the event. Others leave the disaster location in an orderly fashion. Despite the media and film depiction of chaotic scenes, people usually don’t panic.

One should note there is little consensus on the usage of the term ‘panic’. There are basically two visions in the scientific discourse. The oldest comes from daily communication and equates ‘panic’ with extreme and irrational fear. The other opinion sees ‘panic’ as a

manifestation of flight behaviour in which open social norms are discarded (like parents leaving their children to save themselves). In both opinions there are two central themes:²

- Panic is irrational. This position has been heavily criticized by empirical studies which study citizens' behaviour during disasters and fires. The researchers concluded that people usually behave in very constructive ways that are far from irrational
- Panic behaviour is contagious. Again, empirical researchers have demonstrated this claim to be wrong. Sometimes a few people panic, but this feeling almost never transforms into general panic and fear. Very few bystanders 'replicate' the behaviour.

Empirical research concluded that what is thought to be 'panic' is statistically not a phenomenon that occurs in disasters.

In an outbreak of smallpox in New York in 1947, six million people were vaccinated and sometimes they had to wait hours in line or even wait for a few days before being vaccinated. Although some would describe the riots during the smallpox outbreak in 1894 in Milwaukee as panic, it is more likely to be the response of angry citizens to poor management of the outbreak. Examples in the Netherlands where citizens behaved normally were the smallpox outbreak in 1954 or more recently a TBC outbreak in 2005.

Although panic seldom occurs, there are documented situations in which it may happen:

- The perception of immediate and serious danger;
- The perception that only few "escape routes" exist;
- The perception that escape routes are closing, which requires an immediate response; and
- Lack of communication.³

These conditions indicate a situation in which almost no escape is possible. However, in a pandemic, the challenges often come with poor communication from government, public perceptions of the risk and media hype. According to Slovic, infectious diseases can have a high 'dread factor' which heightens concern and worry. That can be further exacerbated when not enough information is provided by public officials.⁴ Another example is 'media-hype'. The American communication advisor and professor Peter Sandman discusses this in great length on his website (www.petersandman.com). Regarding the 2003 Hepatitis A outbreak in Pennsylvania, he wrote: "In risk communication terms, Pennsylvania's hepatitis A outbreak,

² The Sociology of Panic, E.L. Quarantelli, DRC, 1999, pp. 4-7.

³ R.W. Perry, M.K. Lindell, Understanding Citizen Response to Disasters with Implications for Terrorism, in: Journal of Contingencies and Crisis Management, vol. 11, no. 2, June 2003 p. 52.

⁴ Zie bijvoorbeeld P. Slovic, 'Perception of Risk', *Science* (236), 1987, pp. 280-285.

the largest single-source outbreak in U.S. history, is notable for an unusual reason: So far only one reporter has accused the public of panicking. This bad example is too impressive a howler not to document. On November 15, Associated Press reporter Charles Sheehan wrote: “The nation’s biggest known outbreak of hepatitis A is causing such a panic that people are lining up by the thousands for antibody shots and no longer eating out.” His story appeared in dozens of online news sources, mostly under the headline, “Deadly Pa. Hepatitis Outbreak Spurs Panic.” Such a panic that people are lining up? If lining up for shots is panic, what do we call rioting in the streets and breaking into doctors’ offices?”⁵

Myth 2: Citizens are helpless and dependent

In contrary to popular belief, citizens are usually not helpless and dependent during disasters. Often they are usually the ones to start search- and rescue operations, take care of victims and start the first recovery effort. Citizens are just as competent during disasters as they are during daily life.

‘As a whole, human beings respond well at impact times of disasters. People in such situations actively seek relevant information and attempt to do what they can to deal with the exigencies presented by the emergency. The threat of a disaster just about to happen or its actual impact does not paralyze those affected. Passivity in the face of danger is almost non-existent.’⁶

‘Most citizens do not develop shock reactions, panic flight occurs only rarely and people tend to act in what they believe is their best interest, given their limited understanding of the situation.’⁷

Myth 3: looting occurs during and after a disaster

A very strong myth is the one stating the occurrence of looting during or shortly after disasters or serious accidents. Quarantelli discredited that myth as long ago as 1969 (Quarantelli & Dynes, 1969). Since then, he has stated on the basis of empirical research that looting almost never takes places at those times. In the rare cases it does occur, it is done by lone individuals from outside the community (Tierney, 1989; Quarantelli, 1993). Authorities

⁵ Jody Lanard and Peter M. Sandman, Practicing for The Big One: Pennsylvania’s Hepatitis A Outbreak and Risk Communication op www.psandman.com/col/hepatitis.htm.

⁶ E.L. Quarantelli, Community Crises: An Exploratory Comparison of the Characteristics and Consequences of Disasters and Riots, in: Journal of Contingencies and Crisis Management, vol. 1, no. 2, June 1993, p. 69.

⁷ R.W. Perry, M.K. Lindell, Understanding Citizen Response to Disasters with Implications for Terrorism, in: Journal of Contingencies and Crisis Management, vol. 11, no. 2, June 2003, p. 50.

often do take measures to prevent looting. Also, the media often report looting during and after the disaster. These hear-say stories are often even spread amongst emergency personnel.

In the context of outbreaks of infectious diseases this myth is visible in the believe among authorities that citizens will start looting hospitals and will not spontaneously comply with any measure that is meant to prevent spread of the disease.

The strongest measure in combating SARS was isolation: “[A] variety of means were needed to ensure compliance. For example, in Singapore, three telephone calls were made per day to the home of each individual in quarantine to confirm that the individual was there. People who were known to work at night were called at night. Electronic cameras were used to verify that people were at home, and people in quarantine were required to take their temperature on camera. Anyone initially violating quarantine had an electronic tag put on his or her leg (there were 26 cases). In all of the countries, police officers were charged with locating and confining individuals who violated quarantine.”⁸

By fighting infectious diseases such a measure with is regularly necessary is to isolate patients and to put possible contacts in quarantine. For those involved this is a highly threatening measure, because, apparently healthy people can be put together with those who aren't. Communication with those involved and their environment is therefore just as important as using the police.

By adopting the stance that the public will behave irrationally, government minimizes a priori the potential of their contributions during a pandemic or other emergency, and often chooses to limit its communication to the public, thereby reducing any chance for some mutual engagement on pandemic planning or response. These myths thus can contribute to a paternalistic stance toward planning that shuts out community engagement and fails to recognize potential contributions by local citizens.

Finally, elected officials are politicians, who bring their political philosophy, inter-governmental conflicts, and historical experiences with community engagement. Schoch-Spana and colleagues describe other potential barriers to community engagement including leaders' misconceptions that it means they are “giving up power” or that the strategy of engagement is a panacea for all policy questions (Schoch-Spana et al, 2007).

⁸ University of Louisville, Quarantine and isolation: lessons learned from SARS, 2003

5. Community Engagement in the US and Internationally

Community engagement efforts to plan for pandemic flu have been limited in number and scope. To date, there have been two efforts, one focused on policy decisions about vaccines and the other on community control measures during a pandemic. In 2005, the Department of Health and Human Services, in collaboration with multiple organizations and governments at several levels, initiated the Public Engagement Pilot Project on Pandemic Influenza (PEPPPI) to address policy gaps in the nation's vaccine planning. PEPPPI grew out of the assumptions that vaccine policies must be informed by social values and science, that public engagement including experts, community members and stakeholders would provide the most effective means, and that such a process would foster sound policy decisions and public trust (US Department of Health and Human Services, 2005). The process included two national meetings with consultants and stakeholders, a one day public consultation in Atlanta, and three shorter public sessions in Massachusetts, Nebraska and Oregon. Each session began with background information necessary for deliberations and small group deliberations. In Atlanta, with that foundation, participants then engaged in an ethics exercise to identify core values and after discussion, individually voted on their highest priority goals for the vaccine program. A second National Stakeholders' meeting built upon the initial deliberations, reports from participants in the Atlanta dialogue, and new pertinent presentations on multiple topics. Based on their facilitated group discussions, they too developed their set of priority goals and recommendations. Finally, the three state level meetings grappled with the findings from the Atlanta consultation and the National Stakeholders' meeting, and based on group dialogues, proposed changes that were ultimately accepted in the national report.

A second public engagement process was convened in late 2006 by the Association of State and Territorial Health Officials (ASTHO) and The Keystone Center, serving as a facilitator. The Public Engagement Project on Community Control Measures for Pandemic Influenza was also a collaborative effort between federal agencies, state governments, representatives of the private sector, and other groups. The project drew upon the model of the Policy Analysis CollaborativE (PACE), which engaged key stakeholders and community members at large, and focused on the social and economic ramifications of measures to control the spread of influenza.

There have been a few other efforts in the US. In Missouri, an organization, KC-One Voice teamed with four local health departments and the state Department of Health and Human Services. With funding from the CDC, they organized 23 community meetings that

examined community members concerns and developed action recommendations for different segments of the community from official government agencies, private sector, civic organizations and individuals (One KC Voice, 2007). In New York State, the Department of Health has created a set of models for community engagement including Pandemic Flu Town Hall Meetings, mini-summits, electronic town halls among others; to a limited extent, other locales have adopted the Town Hall meeting approach (New York State Department of Health and Human Services). What is not clear is the impact of such meetings. Do they result in a more engaged public? Do they affect policy decisions or planning at the local or state level? Do these communities make strides toward full participation in the partnerships, planning and training necessary to withstand a pandemic?

In Canada, the Public Health Agency of Canada (PHAC) has adopted a citizen engagement approach to health planning more broadly as well as for health emergencies. Using its Policy Tool Kit for Public Involvement in Decision Making, they include the spectrum of activities from information dissemination and education to engagement and partnership, and utilized tools from forums, roundtable discussions, surveys and deliberative dialogues. MacKinnon, in her address to the Disease, Disaster and Democracy Forum in 2006, asserts that citizen engagement constitutes both a means to strengthen social capital, educate citizens and foster more effective policy making but that ideally it also results in more equality and better relationships between governments and their citizens (MacKinnon, 2006).

6. Beyond Policy Deliberation to Capacity and Resilience

Framing citizen engagement in the context of policy decisions on health care resources has largely missed the broader critical social elements of preparedness and response to the potential devastation of a pandemic. History is replete with the ramifications of pandemics for economies, government and social structures. Few authors have appreciated the broader societal impact of a pandemic and the need to call forth creative social solutions. One such call came in Lisbon, where the National School of Public Health in collaboration with the Directorate General of Health and the Institute of Public Health advocate for viewing the pandemic threat as an opportunity to garner individual, social and technological “ingenuity” for an innovative approach that transcends the focus on influenza (what they call the “Flu City”) to “a cidade do engenho” or “city of ingenuity” (Kickbusch, 2006). This approach is a far cry from engagement on policy questions only.

Several others have truly begun to move beyond the limited focus on vaccine availability and hospital beds to what is necessary to create a resilient society. In 2008, the UPMC Center for Biosecurity hosted a forum on community resilience with the purpose of providing guidance to the federal government on operationalizing its directive on resilience as one of components of preparedness (Schoch-Spana et al, 2008). Norris and colleagues (Norris, 2008) define resilience as “a process linking a set of adaptive capacities to a positive trajectory of functioning and adaptation after a disturbance” (p. 130). They further describe the adaptive capacities as resources which are robust, redundant and accessed rapidly; the resources include the pre-existing level of economic development and equity; social capital, social support and community participation; structures for information and communication; and community competence. Essential to community resilience is the need to address social vulnerability, which Cutter and Finch define as “*a measure of both the sensitivity of a population to natural hazards and its ability to respond to and recover from the impact of hazards*”² (p. 2301). Factors that heighten social vulnerability include race and ethnicity, socioeconomic status, gender, age and housing condition. ²

Ensuring community resilience rests on critical interventions:

1. Enhance economic resources, reduce inequities in resources and risks, and address social vulnerability;
2. Engage community members in disaster mitigation activities;
3. Facilitate collaborative relationships between organizations within communities who can be responsive quickly;
4. Foster networks and strategies that mobilize social support; and
5. Engage in planning but recognize the need for flexibility and strong, trusted communication sources that can adapt to evolving situations (Norris, 2008) (Schoch-Spana M. C., 2008) (Quinn, 2008)

As we face the H1N1 pandemic this fall, building capacity and resilience in our communities must begin immediately (Quinn, 2008) with education, engagement, deliberation of these ethical dilemmas and profound policy questions and planning for our civic responses.

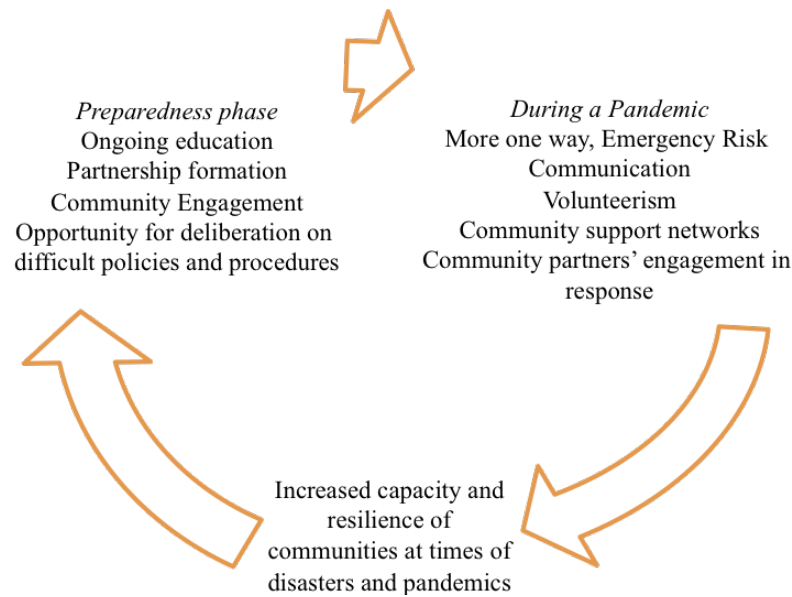


Figure 1: Building Community Capacity for Pandemics and Disasters (Source: Modified from Quinn, 2008, p. 21S)

Although the resilience literature and Quinn’s model suggests multiple approaches to engaging communities, the Community Resilience Roundtable notes that those activities more supportive of resilience, such as strengthening partnerships with grassroots leaders and organizations, fostering volunteer opportunities and networks, and offering communities forums in which to give input into official decision making are the least evident in our current practices. (Schoch-Spana et al, 2008). However, there are examples from which to draw from natural disasters, history and current practice.

Community based participatory research is one means to begin building trust, eliciting community concerns and creating opportunities for partnerships (Quinn, 2008). Participatory methods have been used in addressing natural hazards from volcanoes to floods. For example, the National Research Institute for Earth Sciences and Disaster Prevention in Japan began a new participatory process to improve community engagement in risk management, planning and risk communication in Japanese communities that affected by flooding (Ikeda, 2008). By developing the Participatory Flood Risk Communication Support Systems (PAFRICS), they engaged community members, non-governmental organizations and local governments in increasing community understanding about flooding and trained facilitators from NGOs to conduct community workshops aimed at bringing community members, government, and NGOs together to make decisions about managing flood hazards.

Internationally, we can draw some lessons from the disaster literature on engaging communities in social action that addresses underlying sources of vulnerability in their society. One example stems from the aftermath of the tragic earthquake in Kobe, Japan in 1995. In Kobe after the earthquake, machizukuri (town development) organizations in communities participated in planning for re-development; conducted building inspections; published weekly newsletter on critical information; advocated for special housing for the elderly; and prepared joint housing proposals. Many of these activities were aimed at reducing further vulnerability and strengthening community competence and resilience (Olshansky, 2006).

In California, CARD (Collaborating Agencies Responding to Disasters), established after local natural disasters, focuses on strengthening the capacity of community based organizations that serve vulnerable populations by training CBOs in disaster response and planning, educating community members, and creating networks of local organizations that collaborate during a disaster (Collaborating Agencies Responding to Disasters). Initiated by the federal government, the Citizen Corps initiative has grown in some areas around the US where local communities have formed councils that educate, train and respond to disasters.

Building opportunities to participate is central to community capacity and resilience. In the current influenza outbreak in Maryland, the Governor followed one of the cardinal principles of risk communication, ‘give people something to do’, and in so doing, expanded the state’s capacity to monitor new cases of H1N1 when he announced that teams of citizen internet “flu-watchers” will report flu-like symptoms as part of a new broad based surveillance system. “We have in place an online tool so that anyone in Maryland can become a flu fighter. Their participation will provide (us) with yet another set of eyes to help detect emerging trends in the community” said Secretary of Health and Mental Hygiene, John Colmers (Ruane, 2009). In other communities, local preparedness activities both utilize and strengthen existing natural social support networks by training trusted local community members in preparedness activities so that they can nurture local education and support efforts. For example, in Montgomery County, Maryland, Latino community members, trained as promotoras, meet with other Latino community members and work together on developing individual and family strategies.

While there are numerous efforts of collaborative and participatory approaches to building community resilience, most focus heavily on natural disasters and there is not substantial evidence of efforts that really address the complex and ongoing challenges of a pandemic. Although many governments have begun to recognize “at-risk or vulnerable

populations”, few, if any, have made the more profound leap to recognizing the existing inequalities will exacerbate the impact of a pandemic.

That said, it remains a crucial task to move governments beyond the ‘panic myth’ to a stance in which community engagement can both inform decision making around essential policies and enable efforts that promote the necessary components of resilience. In 2007, the Working Group on Community Engagement in Health Emergency Planning (Schoch-Spana et al, 2007) identified core principles and actions that would foster community engagement in planning for pandemics (See Table 1). We share this as a tool for use in beginning the engagement process. However, it is just a beginning and broader initiatives for resilience require longer term commitment of human and fiscal resources by government and the civic infrastructure both.

Table 1 Top Principles and Actions to Help Leaders Succeed at Community Engagement

Institutional commitment to community engagement
• Obtain the support of elected officials and agency heads; build top-down support for this bottom-up effort.
• Develop a common purpose through joint problem assessment by top officials, grassroots leaders, and residents at-large.
• Position an organizational champion who can effectively handle interagency concerns about the community engagement initiative.
• Grant community partners genuine opportunities to affect disaster policies; back them up with real authority and responsibility.
Investment in an enduring community engagement structure
• Plan for <i>sustained</i> community engagement, resisting shortcuts in the form of one-time or sporadic public outreach.
• Assess local civic infrastructure, identify existing networks, and enhance their capacity to take on disaster-resilience goals.
• Set aside a sufficient budget, support staff, meeting space, partner incentives, and other material necessities.
• Recruit trained professionals to facilitate face-to-face interactions, develop leadership skills in community partners, help resolve controversies, and continually improve community engagement capabilities.

<ul style="list-style-type: none"> • Align expectations between officials and community partners about community engagement scale, scope, process, and time-frames.
<ul style="list-style-type: none"> • Systematically track community engagement’s impact on improved disaster policymaking; provide evidence to officials and citizens that collaborative efforts do matter.
<p>Input from vocal and reticent communities</p>
<ul style="list-style-type: none"> • Consciously recruit and represent groups historically absent in public affairs, including the poor, working class, less educated, and people of color; equip with leadership skills.
<ul style="list-style-type: none"> • Enable citizens to juggle home life and civic life better by offering convenient meeting times, travel reimbursement, child care, public recognition, stipends, etc.
<ul style="list-style-type: none"> • Be receptive to participants’ expressive input, not just their practical advice; people become involved for different reasons: for example, to have a voice, to make a difference, to strike up new friendships.
<ul style="list-style-type: none"> • Acknowledge that participants’ venting of anger is not an impediment to engagement but a prerequisite as a result of unresolved trauma and grief from past events.

Source: (Schoch-Spana et al, 2007, p.18)

7. Recommendations, the insights on citizen participation applied to H1N1

The current H1N1 pandemic unquestionably meets all the defining features of a mega-crisis. Its threat can be severe. While H1N1 is currently a relatively mild disease for most, it can be very serious for pregnant women and those with underlying health conditions such as chronic diseases and immune-suppression. In the developing world, the impact of malnutrition and HIV/AIDS can worsen the current estimates of case fatality rates. We clearly have significant uncertainty as to whether the virus itself will mutate and become more virulent over the next several months. Yet, even with a mild disease course now, there is urgency to ensuring that we have adequate public health surveillance, vaccine development, stockpiling of anti-viral medications, education of the public, and inter-agency or ministry planning for ensuring the functioning of our social and economic systems. Coupled with the key elements of threat, uncertainty and urgency, the global economic recession places additional burdens on governments to manage a pandemic in a time of reduced resources. In the forthcoming Mega-Crisis volume, the editors argue that a mega-crisis requires a paradigm shift in the public policy commitments, decision making

capabilities, and emergency management.⁹ We'll consider these below as we discuss the challenges we'll face in the coming year.

WHO's initial reluctance to move to Level 6 was created when countries and WHO officials continued to discuss raising the level as cause for panic. Inherent in the interim period of deliberation were a number of factors that affect decision making in a mega-crisis: political considerations, the need for scientific certainty, questions about governmental ability to respond, and public reaction. This is the backdrop for consideration of the challenges for leadership in a mega-crisis such as a pandemic.

Resisting the panic myth: This challenge is embodied in the very dilemma that WHO has encountered in June. With member countries urging them to withhold raising the pandemic level, and internal leadership echoing the sentiment, the WHO overlooked the scientific evidence of the spread of H1N1 to multiple continents, and indeed, even evidence of community transmission on those continents, to avoid creating "panic." We argue that 'panic panic' keeps governments from fully informing their citizens and prevents them from both utilizing the existing community capacity and reducing the likelihood that they will engage communities in policy deliberations and planning. Instead, governments must be as transparent, timely and consistent as possible in communication with the public.

Don't equate pandemic with the 1918 pandemic: Frequently, in the media and public discourse, pandemic is equated with the 1918 Spanish Flu pandemic, which was devastating in its ultimate death toll. The comparison with the 1918 pandemic is not useful as it creates undue fear. A pandemic means that there has been global spread to multiple continents. The 1957 and 1968 influenza pandemics are believed now to provide more guidance to what we may expect in the coming year.

Preparing the population for the long haul: One essential role of government is to prepare the population for what could be a sustained pandemic period. Previous pandemics have come in waves of infections, and consequently the emotional and social roller coaster of these sustained events is trying and difficult. Interestingly, engaging communities in preparations, response and policy decisions is a critical means to help them, and help government at the

⁹ U. Rosenthal, B. Jacobs, L. Comfort, I. Helsloot en A. Boin, *Megacrisis*, in print.

same time, to sustain the response. Equally important is engaging communities in recovery in the post-pandemic period.

Resisting the urge to define the “other” as responsible for the illness and barring them from society either at the border or by quarantine: When the H1N1 or swine flu was initially identified in Mexico and then quickly in the US, we saw governments respond immediately with suspending flights, banning travel to those countries, and quarantining incoming visitors, often with only the nationality or travel history as the rationale. History is replete with examples of stigmatizing and blaming others for outbreaks of disease. The WHO explicitly recommends against closing borders and suspending travel. In fact, in our global community, it will be virtually impossible to do so and the economic impact could be detrimental to our economies. However, guarding against stigmatizing the other is also linked with fears about immigration in many countries, including the US and parts of Europe.

Plan to sustain the response for pandemic within and across ministries as well as normal social functioning: Managing a pandemic requires significant cooperation within and across ministries, including those who typically are not engaged when dealing with any other health issue. WHO refers to this as their ‘Whole of Society’ in which requires that all segments of society are engaged in preparedness and response. Ministries of health are obviously essential leaders. However, economic development, transportation, justice, security, emergency management and every other facet of government must also be engaged. Yet the more difficult aspects are how to sustain the functioning of these agencies themselves as the pandemic progresses. We know from the US Centers for Disease Control and Prevention that the sheer volume of demands during the 2001 anthrax attack led to major re-organization in the midst of the crisis in order to manage the response and handle the incredible demands on the staff within the agency.¹⁰ There is a critical need to look internally to ensure continuity and sustainability of government services.

Equally essential is the cooperation of ministries with non-governmental organizations and others to manage normal social and economic functioning over the course of the pandemic. Government must enlist its many traditional partners as well of others with whom it may not typically work. For example, social service and emergency management ministries could

¹⁰ Freimuth, V. (2006). Order Out of Chaos: The Self-Organization of Communication Following the Anthrax Attacks. *Health Communication*, 20(2), 141-148

work together to enlist and support Community Emergency Response Teams (CERT) which are groups of volunteers who can be trained to provide a number of local services such as supporting health care organizations, working in neighborhoods to check on vulnerable community members, and other tasks.

Decision making without public input on rationing of anti-viral medications, vaccines and prioritizing access to care: We have talked about the need to engage the public in decision making on policies, and we have seen the use of public engagement in limited ways in the US and Canada. Engaging publics now has a new sense of urgency as we are no longer talking about the hypothetical pandemic but must now make decisions about who will get the H1N1 vaccine first, who will receive the anti-viral medications when supplies are limited, and how will we manage the potential onslaught of people seeking care. In Australia, they have limited the distribution of anti-viral drugs due to limited supplies. These policy decisions are enormously challenging for two major reasons: 1) there is significant uncertainty with no good estimates of incidence of disease, which also makes it very difficult to estimate case fatality rate; and 2) there is great potential for exacerbating existing inequities and disparities with policy decisions, particularly with access to care issues such as refusing care for undocumented immigrants. Blumenshine and colleagues¹¹ are the first to explicitly link existing health disparities to increased vulnerability in a pandemic, describing disparities in exposure, susceptibility and treatment that create a synergistic effect leading to unequal levels of morbidity and mortality.

For these reasons, continual communication with the public and engagement in the decision-making process will help them to understand the difficult decisions to be made, and will help government to understand the underlying vulnerabilities, reactions and concerns of their citizens.

Managing uncertainty and over-reassuring the public: The panic myth often leads government officials to over-reassure the public, which is exactly the wrong approach to communicating about risk in a pandemic. More appropriate is to talk about uncertainty and then describe how you will manage that uncertainty.

¹¹ Blumenshine P, Reingold A, Egarter S, Mockenhaupt R, Braveman P, & Marks J. (May 2008). Pandemic influenza planning in the United States from a health disparities perspective. *Emerging Infectious Diseases*

Government plans must be flexible enough to change as pandemic changes and tell the public why: This pandemic will last for some undetermined period and without question, plans made today will need to be modified at some future point. It is critically important to recognize the need for flexibility and to talk with the public about how government will adapt to the evolving situation and new evidence. Best practices in risk communication suggest that acknowledging uncertainty and discussing the rationale behind a changing policy will increase public understanding and reduce their anxiety about it.

Using new media: From Facebook to Twitter, news and rumors move at an incredible speed in today's world. Governments will need to grapple with this for several reasons. First, creating some mechanism to monitor the media, including social media, will provide an insight into public concerns and rumors that may be destructive. Secondly, for younger generations, text messages and social media are their means of communication, not traditional media. In the US, the CDC has adopted widgets, Facebook, Twitter and others as part of its risk communication strategy in the H1N1 outbreak.

Seeing the issue as a domestic one only without thinking about external factors and needs: One of the most challenging demands for governments is to balance their domestic concerns while keeping the global nature of the pandemic in mind. A clear challenge to the public's health is the ability of the developed world to assist in the provision of vaccine and anti-viral medications to the developing world. This is not optional as the spread of disease around the world will impact all countries. Yet, it is politically and economically challenging to do so, particularly when demands for services and reduced economic resources are a problem domestically.

Remembering human rights: Balancing individual freedoms and the public's health is at the crux of government response to a pandemic. True community engagement will provide some checks and balances that will help ensure that human and civil rights are protected as much as possible during a pandemic and that more stringent measures of social distancing or quarantine are based on solid evidence on their need and effectiveness.

Remember community assets, capacity and resilience: We have argued that engaging communities in a pandemic will not only enable government to make better policy decisions, it is actually essential to fostering a robust response and community resilience.

8. Conclusions

The Working Group on Governance Dilemmas in Bioterrorism Response sums up the consequences of failure to engage our communities in pandemic preparedness in this powerful statement: “In the absence of an engaged public, resolution of the immediate health crisis is rendered for more difficult, and the social and economic resilience of affected communities is diminished” (The Working Group on "Governance Dilemmas" in Bioterrorism Response, 2004, p. 25). While we agree, we advocate an approach more in keeping with the Portuguese initiative for “a cidade do engenho” or “city of ingenuity” (Kickbusch, 2006) in which we fully engage our populations in the creation of a just and cohesive society, which will serve us well in a pandemic as in more stable times. It is only in a sustained and comprehensive approach to community engagement that we can develop the community capacity and civic infrastructure to allow our societies to adapt the traumas of a pandemic and emerge as resilient communities.

References

- Audi, N. (2009, April 30). *The New York Times*. Retrieved May 1, 2009, from The New York Times: <http://www.nytimes.com/2009/05/01/health/01egypt.html>
- Cameron, D. (2007). Internationalism, Infectious Diseases and International Development: There Is An Elephant in the Living Room. *International Journal of Infectious Diseases*, 11(3).
- Helsloot, I. (2004). Citizen Response to Disasters: A survey of Literature and Some Practical Implications, *Journal of Contingencies and Crisis Management*, 12(3).
- Ikeda, S. S. (2008). Towards an Integrated Management Framework for Emerging Disaster Risks in Japan. *Natural Hazards* , 44, 267-280.
- Kickbusch, I. &. (2006). Flu City—Smart City: applying health promotion principles to a pandemic threat. *Health Promotion International* , 21 (2), 85-86.
- Leavitt, J. (2003). Public Resistance or Cooperation? A Tale of Smallpox in Two Cities. *Biosecurity and Bioterrorism: Biodefense Strategy, Practice and Science* , 1 (3), 185-192.
- MacKinnon, M. What Government Gains by Engaging the Public and what the public gains by Engaging Government. *Disease, Disaster and Democracy: The Public's Stake in Health Emergency Planning*. Washington, DC: UPMC Center for Biosecurity.
- National Research Council. (2006). *Citizen Engagement in Emergency Planning for a Flu Pandemic: A Summary of the Oct. 23, 2006 Workshop of the Disasters Roundtable*. Washington, DC: National Academies Press.
- New York State Department of Health and Human Services. (n.d.). *Pandemic Flu Town Hall Meeting Models*. Retrieved June 2, 2009, from Pandemic Practices: <http://www.pandemicpractices.org/practices/resource.do?resource-id=109&community-id=11>
- Norris, F. S. (2008). Community Resilience as a Metaphor, Theory, Set of Capacities and Strategy for Disaster Readiness. *American Journal of Community Psychology* , 41, 127-150.
- Olshansky, R. J. (2006). Rebuilding Communities Following Disaste: Lessons from Kobe and Los Angeles. *Built Environment* , 32 (4), 354-374.
- One KC Voice. (2007, August). *What is the best way to work with citizens during a pandemic?* Retrieved May 28, 2009, from One KC Voice: http://www.onekcvoice.org/Issues/Public_health/pandemic_flu/assets/Pandemic_Report_Final.pdf
- Quinn, S. (2008). Crisis and Emergency Risk Communication in a Pandemic: A Model for Building Capacity and Resilience in Minority Communities. *Health Promotion Practice* , 9 (4), 18S-25S.
- Ruane, M. (2009, May 8). *The Washington Post*. Retrieved May 8, 2009, from The Washington Post: http://voices.washingtonpost.com/swine-flu-report/2009/05/Maryland_recruits_flu-watchers.html
- Sandman, P. (2009, May 23). *Swine Flu Pandemic Communication Update*. Retrieved June 2, 2009, from The Peter Sandman Communication Website: <http://www.psandman.com/col/swinecomm.htm>
- Schoch-Spana, M. C. (2009). *Biosecurity and Bioterrorism: Biodefense Strategy, Practice and Science* , 7 (1), 1-3.

Schoch-Spana, M. C. (2008). Community Resilience Roundtable on the Implementation of Homeland Security Presidential Directive 21 (HSPD-21). *Biosecurity and Bioterrorism: Biodefense Strategy, Practice and Science* , 6 (3), 269-278.

Schoch-Spana, M., Chamberlain, A., Franco, C., Gross, J., Lam, C., Mulcahy, A., Nuzzo, J., Toner, E, & Usenza, C. (2006). Disease, Disaster and Democracy: The Public's Stake in Health Emergency Planning. *Biosecurity and Bioterrorism: Biodefense Strategy, Practice and Science* , 4 (3), 313-319.

Schoch-Spana, M., Franco, C., Nuzzo, J. & Usenza, C and the Working Group on Community Engagement in Health Emergency Planning (2007). Community Engagement: Leadership Tool for Catastrophic Health Events. *Biosecurity and Bioterrorism: Biodefense Strategy, Practice and Science* , 5 (1), 8-25.

Schoch-Spana, M. (2005). *Realistic Expectations About Public Responses to Pandemic Flu*.

Baltimore, MD: UPMC Center for Biosecurity.

Slackman, M. (2009, May 24). *Cleaning Cairo, but Taking a Livelihood*. Retrieved May 24, 2009, from The New York Times: <http://www.nytimes.com/2009/05/25/world/middleeast/25oink.html>

The Working Group on "Governance Dilemmas" in Bioterrorism Response. (2004). Leading During Bioattacks and Epidemics with the Public's Trust and Help. *Biosecurity and Bioterrorism: Biodefense Strategy, Practice and Science* , 2 (a), 25-40.

United Nations Inter-Agency Secretariat of the International Strategy for Disaster Reduction. (2005).

Hyogo Framework for Action 2005-2015: I S D R International Strategy for Disaster Reduction- Building the Resilience of Nations and Communities to Disasters. www.unisdr.org.

US Department of Health and Human Services. (2005, December). *Citizen Voices on Pandemic Flu Choices: A Report of the Public Engagement Pilot Project on Pandemic Influenza*. Retrieved May 8, 2009, from Pandemic Flu: <http://www.pandemicflu.gov/plan/federal/citizenvoices.html>

World Health Organization (August 21, 2009). [Pandemic \(H1N1\) 2009 - update 62 \(revised 21 August 2009. Retrieved August 23, 2009 at http://www.who.int/csr/don/2009_08_21/en/index.html](http://www.who.int/csr/don/2009_08_21/en/index.html)