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

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Monica Schoch-Spana, PhD

Opening Remarks:

It's a real pleasure to welcome you to "Disease, Disaster, and Democracy." Some people have called it the "3D" conference or the "D-cubed" conference, but our focus specifically is on what we are calling the public's stake in health emergency planning.

Thank you very much for coming. May is a month that is chockfull of competing conventions, conferences, and workshops. So, we are very appreciative of the time that you've taken this morning to join us here today.

I would like to welcome you on behalf of the Center for Biosecurity of the University of Pittsburgh Medical Center and also our summit co-conveners, the Canadian Policy Research Networks, 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.

What I’d like to do in order to open the conference is to say a few words about why we are here. So, why are we here? That’s the first issue I want to touch on in the opening remarks. I also want to discuss reasons for which some people may think that we are here, but in actuality, we are not here to discuss or to promote, as you will see very soon.

This conference is about collective problem-solving and shared decision-making in relation to a large-scale health emergency. Specifically, we are here to discuss the feasibility and the benefit of actively engaging citizens to help emergency planning in anticipation of-first-ethical dilemmas posed by scarcity of life-saving medical resources and secondly, the practical difficulties of protecting the well and caring for the sick in large numbers.

Now, there’s something of a historical and conceptual context for this type of meeting. So, I want to speak very briefly to that. As I indicated, the core concept for the conference is shared decision-making and collective problem-solving. What we are advocating and what we assume you are also advocating, because you made time to attend this conference, is an approach to citizens as capable partners in handling the impact of a large-scale health emergency.

This is a paradigm shift away from the two predominant modes of thinking about how the public will react to either an intentional outbreak of infectious disease or a naturally occurring one such as the pandemic flu that we are now anticipating.

Those two dominant ideas are, first, the notion of an angry mob that has to be contained somehow, and in that context the work of government is one of "crowd control." We are advocating an alternative to the one-dimensional and simplistic way of thinking about how citizens will react when faced with a large outbreak of infectious disease or other kind of health emergency. It’s very easy to be caught up in a very spectacular image of people who are consumed by self-interest, whether they are pouring into the hospital and are considered to be the worried well getting in the way of health care workers assisting those "in true need." Or, the image sometimes takes that of a violent mob that is seeking access to a scarce medical good such as vaccine or hospital bed or antibiotics.

What we are saying is that this is an inappropriate way or an inappropriate assumption upon which to build preparedness and response systems for large-scale health emergencies. So, that’s the first dominant idea that we want to replace with that of the public as a capable partner.

The second dominant idea, which is more productive, but still has its limitations, is that of a public as an anxious audience where the work of government is, essentially, to provide credible communications in the midst of a crisis. What was helpful with regard to experience with the tragedies in the fall of 2001, at least in the United States, is that awareness arose that members of the public were not a problem to be managed, but a
constituency to be served. Awareness through those tragedies, and self-reflection on the
government response, did elicit an interest in improving risk communications and crisis
communications. And that is something that the organizers of this event will heartily
endorse. But, we do want to underscore that crisis and risk communications—while
essential to preparedness, response, and recovery from a health emergency—are
insufficient in and of themselves.

There is something more that needs to be done and that is why we are convening this
meeting, which is to recognize the importance of communications, to recognize the
importance of getting away from the captivating yet unfounded image of a panicked
public driven by self-interest. And underscoring the need to involve citizens as a capable
partner in handling effects of a large-scale health emergency. So, that's why we are here.

I did want to make a few remarks regarding what this summit on citizen engagement
and health emergencies is not about. Just another way of covering the same grounds
that I just did. The first thing that this summit is not about is cynicism or mutual
distrust between the government and citizens. The program again is built around the
ideas of collaborative problem-solving and implementing solutions.

And what do I mean when I say that this summit is not about cynicism? Well, this is a
conference not about a survivalist or rugged individualist credo. The organizing
question is not, "What do we have to do for ourselves because we know that the
government is not going to be there for us?!!" That's the cynicism about our
governmental and public health and safety institutions that, we would argue, is
unfounded, or better yet, is not the kind of foundation for improved preparedness that
we would promote.

Secondly, this conference is not about techniques of persuasion to garner public
compliance with what authorities have already planned. Another form of cynicism, in its
extreme measure, is focused on and can be characterized as selling the public a can of
goods. Those are the extreme things that we are not here to discuss or to promote or
upon which to build a conceptual framework for citizen engagement in public health
emergency planning.

Apart from cynicism, the summit is also not about scare-mongering around new and
emerging threats like bioterrorism or long-standing ones like pandemic flu. I think most
of us are suffering from some form of "threat fatigue." So, recognizing that, this summit
is built upon a realistic appreciation of what can happen in a large-scale health
emergency and what we collectively, as a society, can do about it.

So, we are advocating a measure of hopefulness. We are here to talk about getting ready
and taking action. We are not here to talk about a fear-driven state of paralysis. We want
to stay focused on implementing solutions that all of us can live with if we are faced with
a disaster—a health disaster particularly one involving infectious disease. And that's why
we put "democracy" up there, in the key title, with "disease" and "disaster."
So, thank you again for taking the time to join us here today. I'd like to turn the floor over to my colleague, Dr. Tara O'Toole, who is the executive director and chief executive officer of the Center for Biosecurity. Thanks, Tara.

Tara O'Toole, MD, MPH
Welcome and Keynote Introduction

Thank you, Monica. If you believe the extensive literature that demonstrates what Monica affirmed, namely that the public is a capable partner in dealing with disasters, and has been throughout history-many of you are not only witnesses, but also direct representations of that phenomenon-the question that arises is: how do we make the general public capable partners and active participants in disaster planning, response and recovery? That is the question that we are going to delve into today.

I want to emphasize that we-my colleagues and I at the Center for Biosecurity-have been thinking about bioterrorism and large-scale epidemics since around 1997. We don't regard citizen engagement and participation as an ancillary factor of epidemic preparation and response. This isn't an add-on; this is something that is going to be critical to dealing successfully with a large-scale epidemic, whether it's a deliberate bioterrorist attack, or campaign of attacks, or a large-scale, fast moving lethal epidemic, such as pandemic flu.

Camus said in "The Plague" that it is very difficult for people to imagine human suffering they cannot see. Remember in that story, the town afflicted by plague was behind a wall, and outside the wall, human business went on as usual, inside the wall there was great suffering and calamity and a completely different world. In the modern world, if there is a real plague, we are all going to know about it and we are all going to feel vulnerable.

Epidemics are very different from other types of disasters. They grow insidiously. They don't begin with a distinct flash and boom. The situation in Indonesia right now may, or may not, be the beginning of an actual pandemic of influenza. We don't know; we can't know until we let things unfold. Everybody is potentially vulnerable. This is particularly true if it's a contagious disease, but if there is an attack with anthrax in Washington D.C., you can bet the people in New York and LA are going to feel very vulnerable, as we saw with the anthrax mailings in 2001. Epidemics last a long time; they don't end very quickly and you have to figure out how you are going to sustain vital services throughout that long period. Moreover, we in the modern world-at least in developed countries-have very little experience of large epidemics. We haven't really had to think through how we would take care of each other and ourselves and how we would maintain vital institutions in the course of an epidemic, particularly if we thought that our neighbors and coworkers were potentially lethal, delivery devices of a contagious disease.
We need to understand how critical citizen engagement is to epidemic response, and we need to find new forms of actually bringing citizen engagement to bear. How do we imagine this, how do we organize to do it, how do we make it possible for those who are willing to engage and participate [to do so] effectively?

The speakers and the audience for this conference have been very carefully selected, and I can tell you, in looking over the names, it's a really weird group of people. This is an amazing, very multi-disciplinary collection of people, with a very wide range of experience. All regions of the U.S. are represented, as well as Canada. There are people here, both amongst the speakers and the audience, who have direct experience in a spectrum of modern disasters, including people who were directly involved in the 9/11 attacks on New York and Washington, people who were involved in SARS, people who were victims and responders to the Loma Prieta earthquakes, and many other types of disasters in this hemisphere and around the world. The audience includes activists, academics, health professionals, government officials from virtually all of the U.S. federal agencies, congressional staff and volunteer groups. We are going to try and make this meeting as participatory as possible.

One of the people who I read frequently when I am feeling discouraged and despondent—these days I have several volumes of his work close to hand—is Vaclav Havel, who, as you may know, was an activist on behalf of human rights during the Soviet era in Czechoslovakia. Because he thought it was his moral responsibility to do so, he later transitioned from being an intellectual and a playwright to a politician. He spent a long time-some of it spent in jail-thinking about the modern condition in the post Cold War world and what it meant. He wrote, among other things, that the modern era has reached a point of culmination, and if we are not to perish of our modern-ness we have to rehabilitate the human dimension of citizenship, as well as of politics. This is what I consider to be the principle challenge for the third millennium. He went on to say, in a speech he delivered in a joint session of Congress, that the salvation of this human world lies nowhere else than in the human heart, in the human power to reflect, in human modesty and in human responsibility. He said those words, as I said, before a joint session of Congress six weeks after getting out of jail, and as he held the position of President of the Czech Republic.

I find those words very hopeful, and I hope you will too as we go through today's program. We need [to] make this up, we need to imagine what citizen engagement means, and we need to create the forms and the possibilities that will make that kind of citizen engagement possible, and that's what we are going to start to do today.

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D. A. Henderson, MD, MPH

Why the Public's Trust and Help Matter in Emergencies
Tara O'Toole:

Now, my next responsibility is to introduce the gentleman to my left, D.A. Henderson. Introducing D.A. is always a challenge because he has so many accomplishments and because he has lived so many lives, that reading a litany of them would take a half an hour, but you know him of course as the man who led the World Health Organization's campaign against smallpox.

He has served three presidents, including the current president; he was the advisor to the secretary of HHS and president Bush on bio-terrorism, having been drafted back into the government after the 9/11 attacks. He served for almost two decades as the dean of the School of Public Health at Johns Hopkins University. And he has, of course, a generation-long wealth of experience in dealing with public health crises, of many kinds and in many settings.

D.A. has deep stores of intellectual knowledge and direct experience with disease and the efforts to fight it. He is a guy who, I can tell you, is always focused on what is practical and what is possible and what will work and how to get it done. He is an unstoppable force when aroused, as many of us have discovered. And, he is a true hero of public health. Ladies and gentlemen, D.A. Henderson.

D.A. Henderson:

Well thank you very much Tara, and may I say that it is a great pleasure for me to be here with you because the subject you are discussing, I think, is one of the most important aspects of dealing with some of the problems we face. And certainly as Tara has noted, epidemics of disease do not behave in any way like post-explosive events or hurricanes or what have you. They have a particular life all their own, and they are all very different and very problematical.

Now over the past half century, we in North America have had only a very limited experience in dealing with epidemic disease. We had flu pandemics in 1957 and again in 1968, but neither of these proved to be a serious test of our health system. The hospitals were full, but then we had many more hospital beds at that time and the disease itself was substantially milder [than during] the 1918 influenza. Now certainly the patients were considerably less severely ill than those we are seeing now, suffering from the H5N1 disease in Asia.

In the 1950s, there were outbreaks of poliomyelitis and you have seen the dramatic pictures portraying rooms full of people in respirators, but I think many people don’t realize that in the peak polio year, there were only 25,000 cases of paralytic disease and only a small proportion of those actually had bulbar polio, requiring a respirator. Though there were problems, [they were] very focal, very limited. We had outbreaks of hepatitis and west nile; we have encephalitis, whooping cough, salmonosis, and we could go on and on with a whole host of different outbreaks that we have dealt with, but most of them have been short term in duration. Few of them have seriously tested our system and virtually all of them have been handled pretty much solely by existing
authorities of public health and medical care people, sometimes with support from the Red Cross, but not too often. So seldom has there been real involvement or need for involvement, as it would seem, of the community. However useful it might have been, this has been, some would say, somewhat of an alien concept, involving broadly, community participation.

Now for some 12 years, ending in 1967, I was on the Atlanta CDC staff, with the broad responsibilities for surveillance in the epidemic intelligence service, but the staff was small and we acquired a considerable amount of practical shoe leather experience, in dealing with epidemic problems. But as time has gone on, the CDC staff has grown substantially larger, the number of infectious disease outbreaks have diminished. Expertise at CDC accordingly has greatly diminished, simply not having the practice. And at the same time, state and local health departments have until recently shifted their focus to more chronic diseases, and no less in our academic centers, where indeed we have had very little experience frankly-[and only limited] expertise in the infectious diseases. And all of this became evident when we were dealing with the anthrax attacks of October 2001.

As you will remember, the anthrax [letter] attack-like so many outbreaks of an uncertain nature-was characterized initially by apprehension, completely out of proportion to the inherent risk. We had senior health officials assuring everyone that all was okay, [that] the situation was under control, not to worry when in fact it was apparent to everyone that it was anything but under control, and nobody knew what was happening. There was a tidal wave of press coverage which surprised us more, much as we had anticipated, with far more than anybody ever thought it would be. And much of this was covered by, as you recall, so-called "beat reporters," rather than science reporters, and they were not well informed particularly about science, and very frequently they were communicating with a variety of people who were quite willing to be quoted and who knew even less than the beat reporters about what was happening.

Meanwhile, we had a first responder community who was well trained to decontaminate persons of chemical weapons [attacks]. And so, as you know, for a number of people where powers were-[INAUDIBLE]-they were unceremoniously taken out into the back lot, stripped down, hosed down, isolated, and goodness knows what else. We could not have had more inappropriate behavior if we had tried. We had very little guidance on this as to what should be done. And all of this was covered immediately, and in Technicolor by CNN. So it was not, I would say, one of our more distinguished periods, the anthrax event.

In many cities today, pandemic flu could generate a similar response, because indeed few municipalities have really given serious thought to the preparation that may be necessary to deal with that. And I don't know how many have yet tried to digest the 250-page National Influenza Plan, to try to understand this and what it means to them.

Little thought has been given to the predictable tidal wave of patients that we will see. And little thought has been given as to who is going to care for them, given the fact that
we will have a certain amount of illness in the medical and public health community. It is not rocket science that you need to run through what you might [see], how many patients [that might be expected] based on present assumptions, and to recognize there is going to be a critical need for volunteer groups with elementary training in some medical procedures.... There will be large-scale needs to assure that supplies are delivered, that phone banks are manned to answer the many questions [that will arise], and I could go on and on...

There are still serious challenges barely addressed. And I should add that were a pandemic of H5N1 to begin person-to-person transmission, and as Tara has noted, right now, we are looking out over events, and smartly, with considerable apprehension. A rapidly spreading [active?] epidemic could appear on our shores as early as September, and if we look back to 1957 and we look back to 1918, those two outbreaks really began towards the end of August, early September, and basically spread across the country in roughly two to three months.

Over the past 40 years I have been deeply engaged in dealing with control and eradicate the disease of smallpox, and from 1985 the control and attempts to eradicate a second disease called polio. For the smallpox program we had a World Health Organization budget that was considered quite generous at the time. It was $2.5 million per year, and that was intended to conduct programs in 40 countries. It wasn't enough to buy the vaccine we needed, so we sought donations, but it was a problem. Primarily the endemic countries were the poorest of the poor. They had few resources to contribute. Whether we thought a broad public involvement in this program was a good idea was irrelevant. There was simply no choice but to draw into the program many volunteers from local areas and in many different ways.

For the large-scale vaccination, the technique that we used throughout Africa and other parts of South America was to have a two-person team moving to visit the target areas and seeking [out] the village headman, or the principal religious leader and the school principal in a discussion of how the vaccination program might be conducted, and where it might be held, and what they might do to help organize that, and [to] schedule with them. And it was remarkable, the organizational capabilities they showed. And so in Africa for example we counted on every vaccination. [We were] averaging 500 vaccinations per day, per person with the organization with which they were doing [just] in the villages themselves.

We also found, as time went on, that it wasn't too long before we could train vaccinators in the villages to do the vaccination, and it took a period of maybe 15 to 20 minutes. And then you had expanded your team’s capacity very quickly. What I found very interesting was how responsive and enthusiastic and reliable so many of these people were. They had never been asked to do anything like this before and the only thing we could pay them with was a "thank you" at the end of their time. There was no money involved.

For the detection of cases we came to rely on schoolchildren. This was done by an individual going into the school classroom, showing a picture of smallpox and then
asking the children was there anything like this in their village? What was truly remarkable was how much nine to 12-year-olds know of what is going on in the community, and how willing they are to tell you everything they do know, whether they are supposed to or not. And so, this turned out to be almost more efficient than the reports from health centers and hospitals; it was very useful.

There are a couple of important caveats which we learned very early in the program, and generally apply. The first was never to use the police or the military to enforce vaccination. Any civil authorities were eager to get good coverage, and were eager to have everybody comply. But once [one] brought the military or police in, we found that large numbers departed for the woods or engaged in active fighting with the vaccinators. What we really had that was very effective, was simply further support from the key religious leaders and the school principals and the headman of the village to say that this was a good thing, and compliance was very good. I think the caveat of not involving the police of the military is appropriate today.

The second caveat was never to impose quarantine. That is, forcing contacts with patients who are otherwise well, to be sequestered in their homes or the building. The isolation of patients-that was done routinely. But so far as the families were concerned, we vaccinated them, checked them daily for symptoms, but otherwise they went about their business and moved about freely. When we made efforts to quarantine families, this usually resulted in them hiding cases because they did not want to be quarantined and they would not report cases. And this meant, with greater transmission, we had less chance of containing the outbreak.

Interestingly, talking with some of those in Canada unofficially, who worked on the SARS program where they did try to quarantine families, and were moderately successful, there were a few key people including a couple of the hospital [workers] themselves who had found they had a fever and respiratory illness, but made the decision that they were so key to the continuation of what they were doing at the hospital that they themselves came in and worked.

One can imagine what this might mean if you tried to extend the quarantine to large numbers of families, and how many people, how many professions feel that they are really key and are we going to stay home, or are we going to quarantine, and I would say this is not a good idea. And in fact, I think the suggestion that quarantine had no practical role to play in epidemic control is right, and I think that this is true today.

I think this is counter to certain recommendations of the National Influenza Plan which advises that it might be useful to quarantine families or close schools for three to six months, or close nurseries. It is a provocative idea, but having worked here now for 40 years on outbreaks and wondering how best to control them, I think it is quite clear that quarantine is a concept that is perhaps 50 years out of date, and as we learn from practical experience and understand how diseases transmitted, that this is something that we can happily set aside.
The importance of public involvement in disease control could not be better illustrated than what has taken place with respect to polio and [INAUDIBLE]. The historical importance of the March of Dimes, and the impetus provided by [INAUDIBLE] in raising funds for treatment of polio research will, I am sure, vividly portrayed today at lunch by Dr David Oshinsky who has written his most remarkable book—the best book I know on polio.

As you all are well aware, that set a pattern so that many citizens have banded together to raise funds, in disease research and care for many different diseases. And they are not only donating or seeking the donation funds, but they have made an important contribution in identifying priorities and setting priorities for research through the political process. But there is a quite extraordinary series of events that [they] relate to, and these pertain to polio control and the eradication program.

An interesting approach to vaccination emerged in the 1960s, soon after the oral polio vaccine was licensed. It was an unusual vaccine, such as we had never had before. It was one that required only two to three drops of the vaccine to put on a sugar cube, and then to be put into a child’s mouth. There was no needle or syringe required, and the question soon arose as to why such a vaccine could not be administered by any lay person. And this did not make the organized medical community happy, that might be raised, because it was felt that to administer a product such as this there should be minimal supervision. But it is hard to see how you could go too far wrong with two drops, and if it were six drops it didn’t make any difference. So it was at that point that the [plan set] forth was "Yes, lay people can administer a polio vaccine."

The concept, however, that was proposed was to introduce vaccine by setting up a program to vaccinate all the children under 10 years of age in all of the major municipal areas in the country. Our health departments, at that time, regularly protested that they did not have the personnel to do it, and how could they possibly manage this? When suddenly the Junior Chambers of Commerce, a national club for young executives, volunteered their services and they began working with the health departments. It [became] somewhat of an unusual, tense relationship. Health departments do not work like an industry, and the Junior Chambers of Commerce industry people like to carry things on in a little different way, but it worked. And so began what were called "SOS programs," Sabin-on-Sunday programs, in different parts of the country, and these reached between 80 and 90% of the target population.

Now, mass vaccination campaigns countering epidemics are certainly nothing new, but mass vaccination campaigns for a preventive vaccination such as this was an entirely new concept. Now in the 1980s, Albert Sabin advanced the argument that to control polio, it would be a great advantage in a lot of other countries to vaccinate children throughout the country on a given day. And his argument was that if this vaccine, which grows in the intestinal tract, was widely enough disbursed, it would prevent the wild virus from spreading and thereby it would have a very profound effect.
Meanwhile Albert, in his persuasive way, went to Rotary International and garnered the full support of Rotary in helping to deal with polio. And Rotary agreed, and decided, and set a goal of $100 million that they would raise by the hundredth anniversary of Rotary (which as I recall came up in 2004.) Meanwhile Brazil was dispensing polio [vaccine] in health centers and hospitals regularly, and they were reaching about 60% of the population.

The Brazilians decided to undertake a national program and to vaccinate all of the children that were under five years of age on a single day. This inevitably required participation of a huge number of volunteers, and a whole new set up such as they had never had before. And it was quite remarkable-I suggested that there is something peculiar genetically in the Brazilian constitution, because they can organize programs like this like no other group can do, and they are quite remarkable. They got about 90% of the population. They did it a second time and they have been doing it every year with a great deal of festivity; it is a festival atmosphere. And my colleagues in Geneva in the World Health Organization insisted that no one could keep this up: "It will fall apart, people will lose interest, and you cannot keep this up." Well, year after year it has been kept up, and one of the Brazilians said to me puzzled, "Well, we have carnivals every year, why can't we have vaccination every year?" There is no answer to that.

Meanwhile, the Rotarians have played an important role, initially in providing money in helping the publicity, and also in getting involved in the logistics and providing transportation and many of the door-to-door campaigns; it has been very active. Polio vanished from Brazil. The other Latin American countries began to do something similar, and in 1991, under the direction of the Pan-American Health Organization, and a remarkable physician by the name of Ciro De Quadros, polio vanished from the Americas. This has been taken up by many other countries now, and in fact, the largest number given on any one day was in India which exceeded 100 million vaccinations in one single day. Meanwhile, Rotary’s contributions have now gone over $500 million in support.

This is a heartening story and encouraging, I think, to others. However, I still have the feeling that public health and medical care staff are still somewhat leery of voluntary organizations and have difficulty, very often, in accepting them as full partners in policy formulation, strategy development and so forth. Significantly, I believe, the problem lies in the fact that we have allowed a public health infrastructure to wither in most parts of the country. And as curative medicine has dominated the calendar, public health departments are now typically understaffed, underpaid, and understandably not so receptive to taking on some special efforts that need to be explored, let alone put in place special, significantly different, programs that involve greater communication and involvement with the public and voluntary groups.

But this is changing: In response to national security concerns, the Federal government has begun funding at state and local levels in a broad-based development program for "public health emergency preparedness." This amounts to about $1 billion per year. That sounds like a very generous amount, although they spread this across 50 states and
all the municipalities. It does not amount to huge amounts of money in any given area but it does amount to significant sums more than were there before. Many are responding well. I'm optimistic that more opportunities are there now than there were before, and more will emerge, that will provide closer and more effective relationships between citizens and the public health and medical communities. Thank you.

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**Keynote Address Q&A with D. A. Henderson**

**Joe Dudley:**
Dr. Henderson, I’m Joe Dudley from EAI Corporation. In the past year, the number of countries where there have been human H5N1 [cases] have increased from around four or five fatal cases in a least ten countries. The number of countries where the bird flu has been in animals has increased from less than a dozen to more than 50. Given that the numbers—when the original pandemic influenza plan was written last November—have about tripled during the last six months in terms of human cases, countries, and animal cases, do you think that the current plan is still sufficiently broad and targeted to address the current level of threat? Thank you.

**Dr. Henderson:**
Your point is well taken. I think what we are all concerned about what is going to happen with the H5N1 [virus]. At this point in time, it does not seem to spread at all well from person to person. The analyses that have been done suggest that it is not very far away genetically from what one thinks would make it for an easier spread. What is going to happen from here on, I think, one, it certainly has spread, as you indicate. There is some solace taken at the moment because it doesn’t seem to be spreading so much into Europe at this point in time in the year, but then, influenza doesn’t spread so easily in the summer months. So, what does this mean? I must say we are still very much in the dark about it.

So far as preparations are concerned, I think there is still a lot of thinking to be done about this. There is a national influenza plan, but it leaves a lot of loose ends in that. For example, do we use Tamiflu for prevention or for treatment? If we use it for prevention, you would use the equivalent of ten treatment doses for each individual, because you have to give it every day for roughly ten to twelve weeks, and we don't have that much. Are we going to do as the British do? Their policy is to use it only for treatment, not for prevention. The plan is indefinite about this. It just sort of leaves it open. It’s going to be, I think, very difficult if some areas do it one way and some another way; there ought to be at least some national recommendation on this.

Another thing on this, do we, for example, recommend closing all schools for the duration of an outbreak? That would be at least three months in a community. At a conference just last week, it was suggested we do it as long as it is in the United States,
and suggesting it might be six or seven months [that] you'd close the schools. One of the people leaned over to me and said, "And the murder rate will go up. If you've ever had your kids home for all of the Christmas holiday, then you're ready to send them back!" It's a totally unrealistic recommendation, but we are still wobbling around.

Most important, however, is what we have really not done—I know of no community that has really taken seriously the question of what we do in a surge situation, where we really need a lot of beds, and we have to take care of a lot of people. And not people just sick with flu. You're going to have diabetics that are decompensated. You're going to have people with heart disease or lung disease. Liver disease is going to be much worse. It's going to be difficult to take care of those people. You can't just close the hospitals and say, "We're full up. We can't take any more." That leads to real problems.

I think one of the sessions here is going to be given to that very subject because this is a terribly important area, and pretty much in U.S., it's neglected. I think the Canadians are doing a little bit better than we are. They have a system we don't have a system. We don't have a health system. We have a series of entrepreneurial hospitals, that's it. So it's a different situation altogether. This is where we really need some help in particular.

Dr. O'Toole:
Thank you again Dr. Henderson. It's been a real pleasure, and also for you to represent our experience with modern epidemics and the important role that the public plays in dealing with those types of health emergencies. Again, thank you D.A.

[Applause]

Panel I

What Government Gains by Engaging the Public

Monica Schoch-Spana (Moderator): It's my pleasure to introduce the panelists for our first discussion: what government gains by engaging the public. In this panel, we are hoping to discuss what we mean when we say "citizen engagement" and "community engagement." What are these objectives and how do we obtain them? In essence, why should any of us care about these types of endeavors, whether we are government officials, or heads of community-based organizations, or folks who are just trying to get through their day-to-day lives taking care of their friends and family?

In this panel, we are interested in talking about the enabling conditions for engagement. Very specifically, because our themes are disease and disaster, we want to pose the question of how can authorities bring citizens and communities into policy decisions, as well as actions regarding health emergencies? We are going to hear from representatives
from the public health and homeland security communities about how they and their peers have sought to involve the public in their missions.

It's my real pleasure to first introduce Mary Pat McKinnon, who is Director of Public Involvement for the Canadian Policy Research Networks. Mary Pat will be speaking to us about what does public involvement mean, opening our conversation today about goals of community and citizen engagement; Mary Pat.

Mary Pat MacKinnon
"What Does 'Public Involvement' Mean?"

Last night when I checked in, I was telling the front desk while they were trying to find my reservation, "I'm here for the Disease, Disaster and Democracy Summit." She looked at me and I said, "Oh, actually we are trying to use democracy to perhaps prevent some of that disease and disaster," and she was a little bit more comfortable.

I'm going to be talking this morning more about the democracy piece. Perhaps, if you could just go to the first slide please? In my brief time I hope to set the stage for a more in-depth discussion around citizen engagement in the context of disease and disaster preparation. Right off the top, let me tell you that I'm not an expert in this field. I can say that myself and my family of five lived through the 1998 ice storm at the epicenter in Ontario, but that is a little bit different than the expertise of most of you in the room.

My experience is with citizen dialogues, and we have had quite an extensive experience over the last decade in this area. I am going to draw on that to talk a bit about both the theory and practice of citizen engagement processes; what it means and why it may be gaining more attention and importance. I'll talk about some of the enabling conditions for citizen and civic participation.

Just to very quickly give you a brief snapshot, the Canadian Policy Research Network, the organization that I represent today, is a centrist not for-profit think tank. Our mission is to create knowledge and lead public dialogue and debate on economic and social issues important to Canadians. We have four networks; I'm the director of the public involvement network, and our network is really about three things. We call ourselves "research practitioners" because we are actually in the business of doing citizen dialogues to help inform public policy and to improve civic literacy. But we also undertake research to strengthen both the theory and practice of political and civic engagement, and we try to build capacity.

This morning I want to start with some of the assumptions, and I think it's important to put my assumptions on the table so you can understand where we're coming from. I root citizen engagement within democratic theory. The three assumptions that I think are important for us, at least, [are]...The first is that democracy actually requires citizen engagement or citizen participation for legitimacy. We are talking about both the rights and responsibilities of citizens, but we are also talking about the concept of citizen dignity, requiring the capacity-building of citizens.
A second assumption really speaks to the need for active citizenship requiring a certain level of knowledge. I'm not talking about expert knowledge, but knowledge and skill. Now, the levels of participation, the levels of knowledge and skill, are indeed contested, but most agree there is a certain level required.

The third assumption, which I think is really important, is that with citizen participation and citizen engagement, there are both normative and instrumental or procedural purposes at play. Recently, the American Political Science Association looked at citizen engagement and it came up with four reasons why it’s essential for democracy. Quickly, these are that it enhances the quality of democratic governance by providing evidence of citizen preferences to decision makers. Second is the legitimacy argument, and this harkens back to J.S. Mill's argument that the greater the share of the population that is mobilized and that mobilizes, the more interest that can be recognized. Third is that citizens' skills and knowledge are developed through direct participation, and the fourth is—and this one is a little different—civically engaged citizens can actually provide goods and services that neither the state nor the market can replace.

Moving along, to try and get a bit more specific about where we are coming from with citizen engagement, we root it within the field of deliberative democracy—we have been fortunate to benefit from a lot of very important thinkers in the United States, not the least of which is Benjamin Barber—we know that this has emerged in response to the inadequacies of our democratic practice. It’s important to emphasize that it is not intended to overthrow or replace representative democracy, but rather to improve and evolve it to a higher state. It has emerged out of a very genuine concern about the health and future of democracy as a distinct and cultural mode of life. Barber wrote back in the mid '80s that democracy built on representative institutions, adversarial competition among competing interests, and protection of private rights was weak compared to another tradition, which gave equal or greater emphasis to community action, public talk and civic responsibility.

Getting down to look at some definitions—and I think it is important to take a minute with definitions—we often hear "political engagement" and "civic engagement," and they are similar, but they are not synonyms really. Civic engagement really embraces a broader set of activities and involvement that includes political participation. But we often think of it more as the actions, beliefs and knowledge that link citizens to their societies, and that establish the basis for cooperative behavior; there I am quoting a Canadian political scientist, Brenda O’Neill. Political engagement, or political participation, is really about embracing multiple modes and objectives of political activity, which includes voting and elections, interest group and social movement activity, and protest behavior. I really think we need to be talking about both, but they're not the same thing.

Recently in the UK there was a very important commission called the Power Inquiry. That inquiry's report talks about the need to develop a culture of political participation, where it is the norm for policy and decision making to occur with the direct input from
citizens. I would recommend that you look at that report—it's online—because it's got some excellent suggestions around political participation and civic engagement.

Before I go further, I want to just take a moment and step back and say we all use the words "citizen engagement"—what are we talking about? The two definitions that I am using here I find helpful because they speak to the capacity aspect as well as the deliberation aspect. As you probably are aware, OECD, the Organization for Economic Cooperation and Development, has devoted considerable attention to this whole area in the last half-decade or so. Its definition emphasizes, or recognizes, both the capacity of citizens to discuss and generate, and the requirement for governments to share in the agenda setting. The second definition, which I’ve taken from some CPRN commissioned work, I included because it emphasizes the iterative and interactive nature of citizen engagement processes. These aren't one-off events; really, they are on-going iterative and interactive processes. It's important that we don't talk about citizen engagement or involvement in a vacuum, but remember that citizens exist within communities.

Moving on to the next slide, which talks about what most theorists and practitioners in the field would describe as "attributes" or "characteristics" of citizen engagement. These are that, firstly, it has to emphasize meaningful information, some power sharing, mutual respect and exchange; secondly, that there is an accountability dimension built in. There are reciprocal relationships involved in the whole citizen engagement concept. It involves reciprocity, or relationship building, between the governors and the governed. It offers opportunities for learning, capacity building, dialogue and deliberation. Here in the United States, some of the organizations that have been at the forefront of the movement towards more deliberative processes are Public Agenda, at the Kettering Foundation and the National Issues Forum, which talk about issue framing, naming and deliberation. And finally, the need for value-based discussions that talk about serious choices and trade-offs. After all, at the essence of policy is really the need to choose, and those are some of the most difficult issues that I think we will be dealing with today.

Moving on to the next slide, just quickly, you will all be familiar with this, but I am using the Rowe/Frewer typology of levels of public involvement. I think it is important for us to be clear when we are using terms, because sometimes it is confusing both to the public as well as to the practitioners. If we think of public involvement as a continuum, let’s distinguish levels according to the flow of information. I’m not saying one level is good and the other level is bad; they are all obviously important and serve legitimate purposes. But in the first, "public communication," it’s more unidirectional. We are typically talking about the flow of information from the agencies to the public. In the second, in "consultation," it’s more typically from the public back to agencies. In "public participation," the third level, it's really bidirectional flows, and I would add among the public and between the public and government agencies.

Some examples of the first, for instance, under communication are typically advertisements and press releases; under consultation, you get focus groups, public opinion polls, and public hearings. Then in the third, under participation, in this
country, study circles, citizen juries, consensus conferences, deliberative polls and citizen dialogues. Online engagement is found in all three levels, but most often is seen in the first two levels. Most public involvement to date is concentrated in the first two levels.

In the next slide, I've provided some examples, and probably most of you are familiar with the International Association of Public Participation’s spectrum of five levels. I have included it here as well as Health Canada's continuum which also has five levels; and I have also included a regional health authority in Canada. They're all variations on a theme; the point being that you are usually moving from just that unidirectional into a bidirectional kind of relationship. Some of you may also be familiar with Sherry Arnstein’s "A Ladder of Citizen Participation." This goes back to the 60s. She talked about eight levels; the first two she referred to as "manipulation and therapy," and she called those "non-participation." The next three levels, she said, were "informing, consultation and placation," and she called that "tokenism." The last three: "partnership, delegated power and citizen control," she referred to as a "citizen power." I'm not sure it's quite that stark, but you get the message.

Moving along then, to sort of wrap this into a case...If you can make a case about why engage, I’d suggest to you that there are at least three reasons why it is important to be doing this now. The first is the disconnect between citizens and governments. This is something a lot of us worry about. The symptoms we see in our country, and lots of other western countries, are a decline in voting, particularly among young people, in our country particularly among aboriginal people and ethnic visible minorities, and a decline in trust. We are seeing a pressure for more accountable and transparent public and private institutions. We are seeing a public that is far less deferential, more educated and demand a say. Secondly, an argument for it is that the legitimacy and the sustainability of public policy really do depend on citizen engagement. And thirdly, more effective policies and programs really require-the wicked problems of public policy really require citizens to both define the public interest as well as to implement it.

Moving along, building on that, if we see citizen engagement as both an instrument and an end (I think we should think of it both ways), it’s not just simply a means to foster social capital, social cohesion, contribute to more educated an active citizens. It also is a good in its own right as a way to build stronger democracies and more resilient communities.

Moving to the close, if we go to the next slide-around challenges, if you flip those arguments into what are the challenges, I think these will be familiar to all of you: resistance to change; skepticism on the part of both the decision makers and citizens; low civic literacy; spaces for public dialogue are shrinking; the resources, skills and time requirements; and the research and evaluation skills. On my last slide, I want to end with enabling conditions.

What are the enabling conditions? I think there are at least six. The first is the need for clarity of purpose in objectives; the "why" really does come first. Secondly, opportunities
have to be there for learning and contribution. You have to be able to have some influence. Thirdly, we need to have participatory processes that have quality design and implementation and that are representative or at least, inclusive. Fourth, is the need for adequate resources and realistic time frames. Fifth, transparency and feedback, and the final one, evaluation needs to be built in at the outset, so we can support learning.

In closing, I would say that we need to move from a deficit-focused model to an asset-based model, and it won't happen without effort, resources and a culture shift. I look forward in our conversations to thinking about what needs to happen to align public will, capacity and resources.

Thanks very much I look forward to our discussion.

[Applause]

Karen Marsh
"A National Charter for Hometown Security"

**Monica Schoch-Spana (moderator):**
Thank you very much for a lot of good things to mull over, Mary Pat. Our next speaker is Karen Marsh, who is the Director of the Citizen Corps, which is administered out of the U.S. Department of Homeland Security. We welcome Karen to tell us about what her organization attempts to do in involving and engaging the public.

**Karen Marsh:**
Thank you very much; it's a pleasure to be here. It's a little intimidating to follow such an extensive theoretical discussion on citizen engagement, and then to talk about a program that it is actually trying to achieve many of those things, but I will let you know we have done to date.

As you heard, I do work in the Department of Homeland Security, and I am here to tell you about our principal initiative to engage citizens at a grassroots level. I would like to give you a little bit of history about that, and tell you about some of the recent policy changes and efforts in this area.

Citizen Corps was launched by the President in the State of the Union Address in 2002. It has a very broad, very ambitious agenda. Our mission is, very simply, to engage everyone in America in participating in making the country a safer place. We have always had an all-hazards focus. Certainly in the early years of the department, there was a heavy emphasis on terrorism, but I want to state very clearly that Citizen Corps has always maintained an all-hazards focus to include natural hazards, technological hazards, terrorism, of course, but also any other community safety issues, to include public health issues, and of course, bioterrorism, and anything else to make the community safer.
When Citizen Corps was launched, we focused very definitely on trying to build the local infrastructure to support this engagement. Only so much can be done from the national level, so we have worked very hard to develop the infrastructure throughout the country through the Citizen Corps Council. I am very proud to say, we now have nearly two thousand Citizen Corps Councils around the country, and the jurisdictions that they serve is approximately 72 percent of the country. Now, having said that, not all of these councils are as strong and robust and as reaching out to the public as much as we need to, but we have a lot of things in the works to try to support them.

Very definitely, we are trying to achieve a cultural shift on two fronts. One is to have the federal government, state government and local government first responders reach out to the rest of the community. We are trying to break that paternalistic perspective that it is for the government to respond to the needs of citizens—to break that to reach out to civic leaders, private sector leaders, faith based leaders, etc., to bring them into the process of planning training exercises, again, for all hazards. The second cultural shift, of course, is for the general public at large, and to now make the general public realize that we all have a responsibility to be informed, to be personally prepared, to get training and to participate in the process—so a cultural shift on two fronts.

Going back to the Citizen Corps Council, we at the national level have never dictated, mandated or required the membership of these councils. We want local communities to form the membership of the council as best suits their community. We recognize that every community is different; they have different hazards, different geographic concerns, different population density and different population composition. At a minimum, however, we’ve always said that the council should have representation of government, of each the first responder disciplines, and then, the civic leadership, be it a civic organization, a faith-based organization, private sector, educational system, transportation, critical infrastructure, media, minority and special needs advocacy groups—so it really is for the community to establish the membership of that councils as appropriate for the community. I’m delighted to see that you are going to hear, a little bit later, from Ann Patton, from Tulsa, who has been involved in this from the beginning. You also have Rob Tosatto in the afternoon who is going to speak to you on one of the specific programs in the Citizen Corps.

The council is really the mechanism at the local level; that is to do the strategic planning, to reach out to the community, to engage the citizens, to inform them, to involve them in training, in exercises and the volunteer programs. Citizen Corps’ mission, as I said, is to reach out for public education; it is also to engage the public.

We have five principal programs that are specific volunteer programs that are the interface between citizens and the specific disciplines. We have Fire Corps, which is a volunteer program to specifically support the fire service community. We have Volunteers in Police Service and Neighborhood Watch which is the liaison to law enforcement. We have the Community Emergency Response Teams, which is essentially a 24-hour hands-on instructional course for citizens, and primarily supports emergency responders and management. Then we have the Medical Reserve Corps. Commander
Tosatto is the director of the Medical Reserve Corps; he’ll be here this afternoon. Their mission is, as I said, for public health, but also for emergency medical services. It is for trained medical professionals who want to volunteer their time, but it is also for the layperson with an interest in public health issues. As you certainly heard from Dr. Henderson, there is a role for the layperson who doesn’t have necessarily the highly developed medical skills [but?] that can support in surge capacity for public health and medical emergencies.

As I said, it's a very, very broad and ambitious agenda, and it is very definitely our view that to achieve an elevated level of preparedness in this country that we have got to do this through social networks at the local level. It is important that we provide information nationally in all the websites [and] the plans. Information that is readily available to the public is important, but to really achieve better education and engagement, it's got to be done at the local level through the schools, through the faith-based organizations, civic organizations and the social infrastructure.

Speaking very briefly on some of the developments from the Department of Homeland in this issue...Since Citizen Corps was announced in 2002, there have been quite a number of developments with the creation of the Department. We now have Homeland Security presidential directives that come from the President. HSPD-8-I think there are about 17 of them to date-was specifically on national preparedness, and it directed the department to develop a national preparedness strategy. I am very pleased to say that the general public is a part of that strategy. The general public is referenced in the mission statement and the cascading documents. There is a national preparedness goal, a national preparedness strategy, etc. The goal is being revised, and the role of citizens is going to be elevated in the revised goal, so, I'm very pleased to say that.

As part of this strategy, we also have very specifically identified target capabilities. There is a list of 37 target capabilities that have been released for state and local governments to plan towards. One of the 37, and one of four common capabilities, is "community preparedness and participation." In this target capability, it lays out specific target levels for citizen education. There is a baseline level of universal preparedness: skills, abilities and knowledge that everyone in the country should have for all hazards. Then there is a more specialized level based on risk, so that if you live in an urban environment you need a more specialized, more in-depth knowledge of terrorism, and the consequences of chemical WMD, etc., if you live in a high-threat area. A natural hazard area, of course, you have to have a more specialized level of education on those issues.

Then, there is the volunteer component of the citizen participation level, and that is the volunteer programs that I’ve referenced. These programs are principally an on-going support. It's an on-going augmentation to the local infrastructure, but they are also there to function in a surge capacity when an incident actually occurs. To that point, we have also recently conducted a nationwide plan review. Certainly after Katrina, there had been a lot of documented lessons learned, and one of the immediate reactions from the White House was that we needed to very definitely look at all the emergency plans around the country. This was a very intensive, exhaustive study; we looked at all the
emergency operations plans for every state and territory -- 56 -- as well as 75 urban areas. The phase one report was released to the Hill in March, and the second phase report is going to be released June 1st.

Citizen Corps looked at all of these plans from the perspective of citizen education and citizen engagement, and I will tell you that the news is not good. We have a lot of work to do with respect to the emergency operations planning in this country. We have a lot of work to do to relate the exercises that are going on to the planning process, so that we have a tighter circle between the plan, exercising against the plan, testing the plan, and then feeding the lessons learned with the exercise back to improve the plan. This report is coming out as I said, June 1st; I think it is going to get significant attention around the country. We need to make sure that these plans address all hazards, [and] better educate, inform, and engage the public. Some of the specific areas we looked at were the public education piece, public communications with alerts and warnings, evacuations, mass-care, and resource management.

Some of the other areas that we have included the general public in national policy documents [are] in national exercise program. We have a couple of hurricane exercises that are going on right now in preparation for the 2006 hurricane season, the competitive training grant program out of DHS, and of course, the Homeland Security Grant program.

Citizen Corps does receive line-item appropriations from Congress. I will tell you that our history has been rather checkered, and in recent years it has in fact gone down, but what we’ve been able to do is ensure that all of the funding streams coming from the department to the state and local governments referenced the need to engage and better educate citizens. So again, we're trying to integrate this through the whole Homeland Security strategy.

Certainly, we saw with Katrina there were lots of lessons learned, and again, through the COP review, we know that we need to increase our attention to vulnerable populations. Quite frankly, there just has not been enough attention, specific development on programs and outreach efforts to these populations, and they include a variety, certainly people with disabilities, but also people with language and cultural differences, age-related issues from the very old to the very young, people with pets and service animals, and of course people who have a health issue at the time of an incident.

We are also looking at research, and it’s wonderful to be here and to hear some of the academic theory behind citizen engagement. We’re trying to look at some of the research to look at motivational barriers for citizens. Why is it that citizens are not taking the steps to be prepared? Why is it that citizens are not coming forward and getting training? Why is it that the private sector has not yet institutionalized first-aid training and institutionalized evacuation drills and plans within the private sector scope? We’re looking at a lot of this research. We’re trying to provide the research and the tools to local communities, so they can leverage the research.
Going back to that local Citizen Corps Council, it really is the local community that bears the biggest burden on this. I will tell you that from the national perspective—I’ve been involved with Citizen Corps from the beginning—it is overwhelming to me to see the commitment from the local communities. We have asked a tremendous amount of them in terms of the strategic thinking. We want these local communities to start to document the assets that they have available. We want them to try to segment the community, and to think very strategically about how you reach out to communities, so that you’re thinking about where you have large concentrations of people, to make sure that you’re training people who, for example, work at Union Station. The people who work at the shops at Union Station—if there were to be an attack there, they are the ones who are going to be thrust into an area of responsibility. We need to think a little more carefully about who we’re reaching out to, and who we’re actually training and using in a search capacity.

Certainly with Katrina we saw that there are tremendous benefits to doing this. One of the highlights of the Katrina response was in the Houston area. The Harris County Citizen Corps Council ran the entire Astrodome operations. They absorbed and processed over 65,000 evacuees from New Orleans. They had over 60,000 volunteers who came to the Astrodome setting. They essentially stood up an entire city in less than 24 hours. They had a separate zip code. They had a surgery. They had a post office. It was a phenomenal demonstration of what pre-planning could do. They had MOUs in place; they certainly had a way to reach out to all their volunteers. They had pre-trained their volunteers. They had MOUs for the private sector. They had standby contracts with medical waste retrieval companies. So it is very definitely that the pre-planning and engaging of citizens will pay dividends.

Very definitely, if you have a better informed and better trained public, you will get a better, more appropriate immediate response from the public. With the on-going volunteer programs you have on-going, augmented support for the first responder disciplines, so that the first responders can deal with the more highly skilled, more highly trained aspects of their job. Again, you have the search capacity, if you involve citizens on an ongoing basis, you have the search capacity, people who are trained in an incident command system, know how to function in an emergency management environment. Then of course, through this ongoing outreach, you establish greater trust and greater collaborations, and you will have citizens who listen more carefully and follow instructions and the response phase goes more smoothly. Again, I would encourage you all to look at the Harris County example for a tremendous example of how the pre-planning can make a difference, and that we need to continue to involve citizens in all of these areas.

That’s really, in a nutshell, what Citizen Corps is. As I said, I’m very pleased to see that you’ve got some other representatives here who can tell you more about the practice versus what I’ve told you is the theory. I just want to close by saying that the Department of Homeland Security, working with state and local government partners, is committed to involving the public in all-hazards national preparedness.
Thank you very much.

[Applause]

Panel II

Show Me! An Inside Look at Citizen Engagement

Ann Patton:
Thank you, Denise. Good morning! It is such an honor to be here. I know everybody says that, but I want to tell you, it is an honor for me to be here. And the bad news is that I am much more interested in listening to you than I am in talking. But I will go through very quickly, I hope, some examples of what we are doing in Tulsa.

First, there is someone in the audience I'd like to introduce. Did she come back in? Arrietta Chakos from Berkeley. Arrietta Chakos, right back there. Wave, wave back, Arrietta. Arrietta is, I think, going to be on one of your panels this afternoon. She is the force behind, probably, the best program in the country of the kind that I am going to describe. We call it Project Impact or maybe it's called Disaster-Resistant Berkeley now, I am not sure. But anyway, I think you are going to be very encouraged when you hear Arrietta.

So, here we are, trying to find the processes that can help us avert panic and fully engage citizens as collaborative partners in the process to plan for and manage and maybe even avert crisis. I am from Tornado Alley—from Tulsa, Oklahoma specifically. So first, I want to tell you a little bit about the place that I am in, a look back at how we came to where we are, a little bit about how we go about nurturing the grassroots, about what I am going to call the Project Impact model and why it works even though we now call it Citizen Corps. It is still the same model. A little bit about why it's working in our town, how it's working, some lessons that we've learned, most of them the hard way, and a look ahead.

Our corner of Tornado Alley is in the northeast corner of Oklahoma in what used to be "Indian territory." And if you go back about 75 to a 100 years ago, you are going to find that for much of our history, we had pretty much a disaster a year, most of them floods, some of them tornadoes, some of them... actually we had a terrible race riot. But we were pretty much disaster-prone. And, in fact, in 15 years between 1970 and 1985, we were, I am sorry to say, the nation's leader in flood disasters. We had nine federally-declared flood disasters in just 15 years. Most of you probably think that Tulsa, Oklahoma is like a desert, but actually we have a major river and a lot of network streams that flood into it and a poor history of managing life with the natural environment.
We had so many disasters so fast that that-as somebody said this morning-we were in a kind of paralysis. It seemed like it was the way life was supposed to be. But grassroots activism from the citizen level really got us moving. Great things begin with shared visions. This vision was born about 30 years ago after a 1974 flood when Tulsa housewife Carol Williams called her neighbors down off the rooftops, literally, into her flooded living room and said, "We've got to do something about this." Carol's neighborhood was flooded in 1968, 1970, 1971, three times in 1974, again in 1976, and the last time, thank God, in 1984.

I always call Carol the "Rosa Parks of flood-living management" because she would not take it sitting down. She just refused to accept that things had to be that way every time you turned around. We did not have to flood every year. Her group called itself "Tulsans for Better Community" and others drew on to them like almost a centrifugal force and pretty soon they had mobilized a pretty large segment of the community. I might say that it was never as large as people thought. If you've done citizen activism, you know that part of it is to try to pretend that you are an army when there are really just three or four of you.

Our 1984 flood was so bad. There were 14 people dead overnight and $183 million in damages. 7000 buildings that flooded—that just woke us up. The rest of the community then began to listen to these citizens. We had, I will say, hundreds and, I think, thousands of citizens intricately involved in the planning process for what to do about this problem. Now, we worked very hard since then. Since then, we have not had a negative vote on any kind of flood issue, like a bond issue or sales tax. Since that time....And before then, trust me, nobody could get anything passed. So, since 1992, we've had what we think and, I think probably you could document this, is the nation's leading flood program.

So, now we are taking the lessons we learned in that process, and we are applying them toward other issues. So, you start from the grassroots and you build up. And what we developed were a series of programs. In 1998, FEMA gave the city of Tulsa a seed grant to create the Tulsa Project Impact program. Most of what I am going to talk about today, I'll probably say that the name is Project Impact even though it has been changed because in the year 2000... I am sorry, the year 2002, we got a grant that would create a Citizen Corps program and because of the name confusion, we pretty much shifted to Citizen Corps. But we also created a 501c(3) called Tulsa Partners to mobilize the private sector and private dollars. So, we have three names and it's confusing. So, what we are just going [to call it] for today is what most people call it, Project Impact.

Today we—and I am actually retired, but I still consider it a "we"—we have about 400 partners and 1800 volunteers, and another 1000 in the Medical Reserve Corps. And I want to talk a little bit about that later. The new Administration killed Project Impact as a national program in 2001, but some of us actually never caught on to that and it's still alive and well in a lot of communities. Right, Arrietta? It's still alive and well in a number of communities, sometimes in different forms, often with other names. In Tulsa, we are working with the private and public funding sources on a pretty broad
slate of programs and projects, all around one central theme, "How do we create a
disaster-resistant community?" The key is that everything is done through partnerships,
starting at the grassroots level and moving up.

The title [for today's talk] "Grassroots Hazards Managements" actually comes from
Monica, but it's a good one. To me it means what can ordinary citizens do to protect
themselves, their families, their businesses, and their communities from a whole
smorgasbord—that overwhelmingly frightening array of natural and man-made hazards-
from tornadoes to terrorism to bird flu. How can they do this as volunteers and as full-
fledged community partners? That's our mission.

We are all working together to build a safer and better community that is sound, safe,
and sustainable. Let me tell you a little bit about this model and why I think it works
well. I want to describe a few of the features and I'll say that to me it is based on
something that supposedly Mark Twain said. I always thought it was pretty good:
"Everybody is smarter than anybody." [That's] sort of our base [for what we do]. That's
how we began our thought process.

Project Impact was FEMA's grassroots community mitigation program. It existed—it had
a life-span from 1997 to 2001 as a national program. It was working well in 250
communities before it was aborted. And how did it work? They cast somebody around
the country, created seedlings, nurtured them, nurtured, nurtured, nurtured them and
identified and worked with communities' spark plugs. They empowered bottom-up
management, encouraged program ownership at the local level. Locals absolutely owned
this program. It operated more like a jazz band than an orchestra. It would be pretty
hard, a lot of times, in a lot of our communities, to find out who is in charge-[it] didn't
matter because everybody was doing sort of their own improvising thing. It inspired
a lot of enthusiasm and excitement across the country and linked together those people,
like Arrietta and me, who were excited by this program and wanted to figure out how to
make it work.

Ok, looks like I am almost out of time, so I am going to speed up.

A little bit about how it's working. Public enemy #1 in Tulsa from the citizen's
standpoint is Tulsa Homebuilders. [There was a lot of] bad blood between the builders
and the citizens. Project Impact actually brought us together, amazingly enough,
because we began to work together on a program to put safe rooms in homes in Tornado
Alley. We have one of the worst tornado risks in the world. We have no basements;
figure that out! Safe rooms are small, closet-like things anchored and armored to protect
you in a tornado, and they can be above ground or below ground. So, since then,
actually, thousands have been built around the state. The important thing is that we
learned how to attack the problem instead of each other.

[Note: Referring to slide image] This is Don Staley. This poor guy lost three homes in
five years to tornadoes in More, Oklahoma. By the third one, he had built the safe room
and he survived in it. Now, he is selling them. The secret to this community in More,
Oklahoma surviving all of these is: one, they have more safe rooms per capita than any place in the world; and two, neighbors take care of neighbors. They literally open their safe rooms, open their shelters, [and] invite people in.

A "McReady" program does what I think you all were talking about earlier. Our goal is to take our program to the people. In this case, into McDonalds one month out of the year-170 McDonalds stores, 1000 customers per store, and the message is: "Yes, you can be prepared." A Millennium House was inspired by Project Impact. This is a house for the poor. It's about the cost of a Habitat house. It's disaster-resistant, energy-efficient, [and] utilities are about $100 a year. Citizen-based, OK?

The Ecosafe home again [note: referring to slide images]...trying to take our programs to the people where in the process of creating a home to show how to live safely in Tornado Alley, without wrecking the environment. It will be built at the Tulsa Zoo. Why? The Tulsa Zoo has 550,000 visitors a year. We want to be where they are.

Human Response Coalition [note: referring to slide images]...: 50 social service agencies, all working with us, amazing programs to try to get to the more vulnerable populations.

Other examples....I will just say that there are a number of wonderful examples around the country, I wish I had time to go into more of them.

Lessons learned? People will, I think, mobilize around the common vision or against a common enemy. And, in this instance, we've been able to use both of those. The enemy is disaster. The common vision is that as we work together, we can actually do something about it. I think [that] I'll end there.

Denise Gray-Felder (Moderator): Thank you very much.

Denise Gray-Felder (Moderator):
Okay, next we have Roger Bernier who is currently with the Centers for Disease Control, Co-chair at the Public Engagement Pilot Project on Pandemic Influenza, and Senior Advisor for Scientific Strategy and Innovation. Roger?

Roger Bernier:
Good morning! As a scientist at the Centers for Disease Control, part of the way I got into this was a little bit abrupt. I was testifying at a Congressional hearing when one of these citizen advocates told me that my research from CDC was dead on arrival. My reaction was, "Atlanta, we have a trust problem!" Because it didn't seem to me that more research was really going to help the situation.

So, it was a wake-up call for me that, really, facts do not always speak for themselves and that values are also important, at least for some science-policy questions. I am not proposing public engagement on which flu virus we should put in the next year's flu vaccine. But I think there [is] a subset of science-policy questions where we basically
need to try and pass two tests: we need to get the science right, but we also need to reflect the right values.

Another interesting framing for this issue is to think about this (at least for scientists)...I think this is potentially more attractive, that we have a "know-do" gap, if you will. It's kind of the challenge of knowledge translation. What we know does us no good if it isn't put to use. And if we can think of public engagement as a strategy for solving this "know-do" gap, I think this is one way of appealing to people who are primarily oriented towards evidence. In any case, this was a beginning for me of a journey in a democracy zone. [These are] travels that really haven't ended yet and it has been a very fascinating journey.

I'd like to begin with the quote which I think summarizes part of the motivation for this: "When big things are at stake, the danger of errors is great. Therefore, many should discuss and clarify the matter together, so the correct way may be found." And for me, one of the most astonishing things in that is not only the wisdom of it, but the date of the quote, which is over 1400 years old.

Well, one of the things that we were able to accomplish in this exploration is an actual testing of a model that we had developed a couple of years ago. And the first, real-life, policy issue that we addressed was the issue facing us about ranking priorities for the use of limited supplies of pandemic flue vaccine. The question we posed was, "Who first will we vaccinate against pandemic influenza when vaccine supplies are limited at the outset of the pandemic?"

Now, the key features of this model and this project-and this is a condition that I added recently-[is that] there shouldn't be too much polarization. On the other hand, there needs to be some difference of opinion. Otherwise, it may really not be worth doing. So, I think there are a vast number of questions in this middle zone where we do have differences of opinion and where, I think, this kind of approach can be helpful. As I said, this is not for all issues, but with issues where values are at play in the decision. The model we use is the one which involves both stake-holders-that is, people who belong to an organization or represent organized interests-as well as citizens-at-large who have no recognizable agendas related to the question at hand.

We have to have participants who become well-informed on the issue. We are talking here about informed discussion. We are not, on the other hand, trying to make experts out of everyone, but there does need to be a basic amount of information that people have. If you refer back to Mary Pat MacKinnon’s spectrum work—one of those spectrums that came up this morning—we are trying to do this at that middle level of engagement. [That is,] an interactive level that is beyond what you get at focus groups and polling, but is not necessarily all the way to the end where you are delegating the decision to outsiders.
I think having independent and balanced fact-finding is important, and [so is] the presentation-neutral facilitation. And [something that] I think [is] very important [is the] participation of government and commitment of government, so that this is not talk for the sake of talking. This is talk that is designed to inform a pending decision that is going to be made. So, it's an opportunity to shape a real-life decision. And one way to help to make sure that happens is to have clear linkage to decision makers.

The approach we use was really one that required—because we are a pilot project, we are not very well funded—we really had to work together to make this happen. And in fact, I notice that some of the attendees in this meeting [were] actually participants, at least three or four people. But we had at least 15 different organizations participating and contributing different services or goods or expertise to this project and they are all listed here [note: referring to slide image]. There were five phases to the project. Again, [I want] to remind you that we had both stake-holders and public.

When I first got into this field early on, someone said, "You are going to come to a fork in the road very early on and one fork says 'Citizens' and the other fork says 'Stake-holders.' And you are going to have to make a choice." So I did the Yogi Berra thing and said, "When you come to a fork in the road, take it." And so, we designed the model that would include both publics, because this is one big question in this field as well, "Who is the public anyway?" But I think most people agree it has these two major arms. So why not include them both?

The five phases then included a meeting of stake-holders who would help to frame the issue. Then an entire day devoted to deliberation on the part of citizens. Then a stake-holders meeting for the second time to make up their minds, but now informed by the input directly from the citizens. And then because of numbers' problems, we could only have limited numbers to add to our credibility, we took this out on the road to the four different parts of the country and actually presented our deliberations—our verdict, if you will—to citizens to ask, "Does this pass the laugh test? Is this something you citizens can live with?" They didn't deliberate to the same extent as the original two groups, but they did filter the results to make sure that these were compatible with their views as well. And then, finally the feedback that we got from those sessions was incorporated by the stake-holders again into a final report.

How many people did we attract to this? Well, the deliberation day in the South—it was done in Atlanta for budgetary reasons, [and] we were able to attract over 100 citizens. This was on a Saturday, with no money. They came at 8:30-9:00 in the morning and spent the entire day going through the different phases of the exercise. In Massachusetts in the feedback session, there we had those numbers and you see the other numbers for the other parts of the country [note: referring to slide images].

As far as the stake-holders, we had a group of approximately 35, and they represented all of the stakeholder interests that we could identify—the health professionals, the federal agencies, industry, the vaccine industry in this case, consumer advocacy groups, state government, and minority groups.
What was actually the work of the citizen? What did they actually do?-because I was told the focus of this session should be to give you an idea of how we did this and not the theory. Well, first is the learning part. And here, we were very lucky to have a really outstanding speaker who was able to come in, and in an hour and a half approximately, give Flu 101 basically to these citizens, [and] do it in a way that was very successful in communicating to them, was not condescending, made people feel comfortable about the information they were getting, and was able to allow a question and answer period.

In addition to that, we had in advance worked hard to identify what we thought were the most important things that people needed to know about influenza in order to have an informed discussion. And we were able to boil that down to twenty different topics, [and we] provided that information to them in advance. And then we did-to warm them up to the kinds of dilemmas they were about to face-we did an exercise in values dilemmas that had been constructed by an ethicist from Harvard that had been used earlier with the stake-holders which was very effective in getting people to understand the kinds of tough choices they were about to face and also the values that were going to be in conflict.

Then, we had small group discussions for five choices: save the most lives, assure the functioning of society, protect the young first, first-come first-serve, or use a lottery. Those were the topics they were asked to choose on and discuss. They-individually after discussion at these tables-were [then] each given three dots on which they could vote for one or more of the five choices. They didn't have to put all their dots on one but could split it out. And then we had further discussion in the plenary session.

The stake-holders, as I said, framed the issue. With that group, instead of giving them only five choices, we actually split out the how you assure the functioning of society and actually gave them more specific societal functions, such as "assure public safety" or "maintain emergency or life saving services," [or] "protect the key leaders of society". We had a question about the objective around protecting homeland security and so forth. They then ranked the goals in order of importance, one at a time, starting with the most important by placing dots next to the options. And then we had a large group discussion to analyze and refine the voting results to make additional recommendations...

I'm getting harassed by the moderator here so I'm going a little fast.

What were the results? Well, the first choice thought to be the most important function was to "assure the functioning of society," followed by a close second, which was to "reduce individual deaths and hospitalizations." This is interesting for a number of reasons because the experts were deliberating separately and independently and actually came to a reverse decision. I think it's fair to say that the experts had ranked number two as the number one and one as number two.

But the citizens in ranking number one first, were very cynical and they wanted to make sure that we were able to accomplish that first goal using the minimum number of doses
to accomplish the task. They didn't want every Tom, Dick, and Harry, claiming that he or she was essential to society, but they recognized that was the number one priority. And the other goals: lottery, first-come first-serve, really scored much lower.

In terms of impact, one piece of evidence that we have—as you know the HHS recommendation in November of last year basically went with the expert opinion—but they did have language in the narrative accompanying the expert recommendation, which I think was indication of the fact that we were considered. HHS has recently initiated outreach and engaged the public—a theme that has emerged is the importance of limiting the effects of pandemic on society reserving essential societal functions.

Basically, HHS—and my interpretation [of this]—was [that they were] leaving the door open to say, "This is still under discussion," and encourage more discussion.

I'll skip this [note: referring to slide], but basically let you know we were fortunate to have an independent evaluation simultaneously and it basically has been a very favorable evaluation.

The conclusion from our project: we obtained proof of principle at least for the vaccine community. I think this proof perhaps is already there for those who are in the deliberative democracy field. But for the vaccine community, we obtained proof of principle that public engagement is possible and useful to decision makers.

I think the evaluation is not over; there are other ripple effects from this. It turns out [that] the HHS guidance [released] last November is not going to be the final say. It's now being referred to as "interim guidance" or "preliminary," and we are as a nation committed now in the latest plan to go through this again with the final guidance scheduled for 2007. At the state level there is a possibility we will be working with some states who may want to engage in this also. North Carolina has already undertaken something on its own and CDC has expressed an interest in doing a project where we would get citizen input on the tough choices we make around social distancing. And we plan to do another project on that. And this morning you heard about the plans in Canada.

Thank you.

Denise Gray-Felder (Moderator):

Thank you, Roger. And our final panelist is Reverend Kristina Peterson, from Mississippi Delta. Is that a correct way of raising geography or no? Which delta?

Kristina Peterson:
The Birds Foot Delta at the end of the Mississippi River.

Denise Gray-Felder (Moderator):
The Birds Foot Delta. Ok, Kristina. I’m sorry! I forgot the introduction.
[Laughter]

**Denise Gray-Felder (Moderator):**
Kristina is the organizing facilitator of the Grand Bayou Families United, a Presbyterian Disaster Assistance Volunteer and is currently a doctoral student and is obviously a member of the clergy as well.

**Kristina Peterson:**
Thank you. In preparing this presentation today, I am standing here with 150 people, because 150 people helped put this presentation together. And, as being a "level-five DNA" group [note: a joking reference to morning talks by Chatigny and MacKinnon on the different levels of public involvement], I want to tell you, first of all, it's very, very messy when you involve all the people... when you're participating in level five because everyone wants to have input! And I have three messages on my cell phone with information that they didn't want me to leave out. So, citizens' participation is great!

And the other part I want to tell you so I do not miss it later is that when citizens' participation really starts to activate, it just keeps increasing with more enthusiasm. ... Maurice, Thomas, and Paul are the ones who called me this morning to make sure to tell me, to tell you, that while we are here meeting, they are going to talk about infectious disease and a flu epidemic while bringing in their shrimp. These are folks that everybody in society has basically written off by saying they are folks not educated enough too understand the dynamics of disasters.

Grand Bayou is way down on the Bird's Foot Peninsula, an hour and a half south of New Orleans. They are part of a Native American community that is spread across the coast of Louisiana: The Grand Bayou is Atakapa and Houma. They define their multi-generational community as kinship, tradition, culture, sacredness of place. As one elder has stated, their strengths are: everybody has more than one mom and dad, they live into their 80's and nobody goes hungry. The community has been together and in place for a long time, they have history, they have a shared vision, [and] they have incredible environmental analytical skills. They know what happens and how it happens because their lives depend upon it. So, their analytical skills are incredible. They have knowledge of food resources, and as one person said, "You know, is it redundant to say, 'It takes a village'"? Of course.

This is their "wharf net" (a large net attached to the dock for fishing). They never go hungry because they have the wharf net. They can go out and catch lunch, or dinner, or anything else, at any time during the day-and that's one of their homes [referring to slide image].

A lot of seafood (30% of what the U.S. consumes) and other resources come from the bayous of Louisiana. This table prepared for us for an event [note: refers to slide image]- which is so abundant-reflects the harvest of the surrounding marshes.
They have a school bus-school boat you could say—that takes children and adults to the shore. They are a totally water-locked community. One person said, "You can’t separate us from the land. This is who we are. This is what we know: We love the land, the water, the birds. To live anywhere else is to die. We have a vested stake in what happens here."

The community is committed to work on restoration because they are vested in this area. After [Hurricanes] Isidore and Lili in 2002, their community was devastated. They did not want to just use usual modes of disaster recovery—they wanted an integrated approach to all the issues that were around them.

So, they formed a non-profit organization, Grand Bayou Families United in January 2003 and had their first visioning meeting in April 2003. They then decided they wanted take community action to address their concerns—after they saw different ways and models of which to work with outsiders—they decided on the process of a participatory action research collaborative.

Then, in August/September [of 2005], you knew what happened with Rita and Katrina: Lower Plaquemines Parish was totally under water, with a 21 foot wave that totally inundated the entire region. The issues for them were loss of place, culture, and loss of traditional ecological knowledge. They know very well there is global warming, coastal erosion, hypoxia. Birds are dying before making landfall in the gulf. They see loss of species. They see different behaviors in wildlife. They know something is going wrong.

For generations the community was self-sustaining. Their pain is that they have only recently become a subsistence colonial economy because of the ways in which the outside society has been treating them. They also said they wanted to make sure that you do not eat shrimp that have more frequent flier miles than Bill Gates. They said, "Buy local shrimp; they're better."

They're sinking: Loss of marsh, extraction from the oil, and the lack of rebuilding of soils, has made them extremely vulnerable. After Rita and Katrina, 60 plus square miles of land was lost in Plaquemines, also making more vulnerable New Orleans and the rest of the coast.

This is the nightmare that they really wanted you to see [referring to slide images]. These are all oil platforms, oil wells, and oil pipelines. This was in 1999, and since then, many more have been built. This is all another disaster waiting to happen, with all kinds of other issues. This is what happens when canals and channels are cut through the marsh. The Grand Bayou is a little strip in the center part. As canals and channels are cut through the marsh, the land disappears.

My Bayou colleagues also wanted me to say that many people—many at-risk, vulnerable, and marginalized population groups—are in their situation because of social, economic, and political pressures and policies. And so, when you address vulnerability at an agency, you may be putting the population at greater risk if they [at the agency] do not understand the underlying political and social forces and provide for sufficient...
community participation. It is extremely important because, as people become very
vocal and start taking charge, it can be extremely threatening to all the powers that be if
the agencies and political bodies are not ready for active democratic participation.

In December 2003, we started building a team of "participatory action people"-people
from universities, businesses, government agencies, faith groups, and others. They
collaborate with the community folks who have the traditional ecological knowledge.
Participatory action is a trust; it's not superficial. It walks alongside the community for
[an] extended time. It is collegial engagement. It listens, learns, teaches, modifies,
respects place, ideas, cultures. It's transparent in communication. It's [being] in with
each other.

All the people who are involved from the outside have pledged they will not write or
author or present anything about the Grand Bayou without the full participation,
knowledge, and consent of the Grand Bayou.

It takes patience.

Here is Dr. John Pine (LSU) showing maps [note: refers to slide image] that Mashriki
Hassan developed from GIS mapping of the Grand Bayou. The Grand Bayou folks are
looking at the maps and sharing their knowledge about flooding and storm surges. LSU
was able to refine their maps as a result of the community's local knowledge of surge
patterns.

Collaboration is working together for solutions through education, training,
participation in conferences, tutoring, personal investment, commitment, faith,
friendships, and sharing traditional knowledge with others. The community is really
working for sustainability of environment, economy, and culture. Sharing their
knowledge through eco-touring is one of the ways in which they decided that they would
try to educate outsiders and teach people about the issues facing not only themselves,
but the entire country. And so, we became the first Ecotour.

The other part is participatory strength and risk analysis through community oral
history sharing and recording. When you're doing this type of work, participatory
analysis is not just looking at the risk, but it's also looking at the strength. And the
strength of this community far outweighs any of the risk that it has or that it sees that it
has. To walk into this community and [to] recognize that strength and knowledge puts
the community at a much different footing than going in and saying, "You have a
problem" or "You are helpless."

So-lessons learned: Conflicting models have conflicting outcomes. There is need for
continued work between friends of Grand Bayou and other outsiders. Constant
challenge of finding funds that enables the work to continue. Differences in
philosophical approaches will have diverse outcomes.
Community action has philosophical approaches that can be harmful [or that] have been traditionally in the past. [For example], an outsider comes in and imposes their own values system. Or, somebody comes along with a grant and says "This big money is a big fix." Or, a philosophical approach that goes against the very being of their community that wants them to act in ways that are counter to their own culture.

They also see that an expert-PU really wanted me to underline this one—an expert is arrogant and ignorant because they do not understand the talents and abilities of the local community. The other thing that we hear constantly, and Roseana can tell you more about this, is that an expert is usually a carpetbagger that doesn't listen and doesn't care. So those are the local observations made about experts and they see the experts as being "anti-peer." Keeping ourselves intact as the outside friends—of which I’m one—we constantly regulate ourselves so that we do not become experts.

The Bayou has presented its concerns for stabilization of the marsh and preservation of its cultural heritage to such groups as the National Hazards Workshop, Corps of Engineers, Legislative Representatives, National Rivers Association, Academies of Science, and over 100 students from three different universities. These are folks who society has written off, saying they are ignorant and have no ability and yet they have worked with people from Oxfam, National Council of Churches, Organization of American States, Social Enterprise Alliance, National Science Foundation, Native American [Inaudible], Sundance...

In this last story that I will tell you, Sylvia is standing here with the man that headed up the fire department of New York City who handled all of 9/11[note: refers to slide image]. They met at National Hazards, and he said to her, "Be creative and take charge."

She was left in the Office of Emergency Services as a dispatcher after Katrina-right before Katrina. Her boss evacuated, left her, and four other women at the Center. She said "Okay, I'm taking his advice. I'm going to be creative. I'm going to take charge." She called around the entire region of the South Plaquemines Parish where the water surge came over, and she identified who was staying, where the boats were, where the keys were, where gasoline was, and she rounded up the "Cajun Navy."

The percentage of death in Lower Plaquemines was much lower than any place else along the coast, and it was due to her innovation and her ability. These were the boats [note: refers to slide images] that the Grand Bayou used [and] lived on for eight months with 49 people. The oldest one being 93 years old. The youngest one was only three weeks old at the time of the hurricane.

This is the toxic waste dump behind where their boats were located.

They asked FEMA for trailers—they never came, so they innovated. They found junk buses, they found these appliances that were thrown out in New Orleans, and they provided [for themselves] so that they had healthy, safe conditions. So they were creative.
The people have continued to meet and deliberate on their safety and take charge of their future. What they envision is a healthy, bio-diverse community with green energy, green houses, [and a] lifestyle that is sustainable and good.

And the kids said, "We want a healthy Grand Bayou. We do not want drugs. We do not want alcohol, pollutants, poachers, or junk food. Thank you." Community engagement starts early: This was from Emily, age 2 [note: refers to slide image].

Thank you.

David Oshinsky, PhD

Polio as the People's Disease

DA Henderson: David Oshinsky...is listed here as the George Littlefield Professor of History at the University of Texas, although he does spend a good bit of time in Pennsylvania—but that's a long story—where he taught some time before. He's the author of two books. One is The Conspiracy So Immense: The World of Joe McCarthy. He then went on to talk about crime and punishment in the south, Worse Than Slavery: Parchman Farm and the Ordeal of Jim Crow Justice. Both of which won major prizes and were New York Times notable books.

He wrote the book called Polio: An American Story. I have read it and it is the best book on the whole history of polio and one of the most dramatic. The whole saga of polio...it's just remarkable that many people don't appreciate what an influence this has had on the research in America, on philanthropy and many other things, which he will talk about. Yesterday, that book received a Pulitzer Prize.

[Applause]

I'll add as a note, and I'll remind you again that he is prepared to sign right after this. There are books out there, which you can buy at 20 dollars, rather than 30, and he will be happy to sign, so we'll see about that at the time. It says cash, credit cards and checks accepted, and probably barter is not acceptable. At any rate, it's a real great pleasure to have David Oshinsky here, and I'm sure you will enjoy this as much as we've enjoyed talking with him. David?

David Oshinsky: Thank you for having me. When most people think about polio—I'm looking around the room, there are here my age and above—I know people born in the 1960s and after tend to think of polio as a vaccine. Those of us who were born earlier than that see it as a disease. I grew up—and looking around, as many of you did—in the years before the Salk vaccine and the Sabin vaccine came to fruition. Those were frightening times.
It was for me, and for millions and millions of children, in particular, a time when summer would come and a plague would descend. We couldn't go swimming, we couldn't go to the movies, and we couldn't play with new friends because they might have the virus. Newspapers in my town, in New York City, actually kept box scores. They'd start around Memorial Day and they'd go through Labor Day, and they would actually list the number of kids who had come down with polio each week.

I'll talk a little bit later about some of the number of people who contracted polio. It wasn't quite as widespread as you might think. Indeed, it was the March of Dimes—a truly revolutionary philanthropic organization—that helped turn polio into a national crusade following world war 11—and, perhaps, into our national obsession.

Polio is a virus. It's an intestinal infection. It's caused by contact with fecal waste, unwashed hands, shared objects, contaminated food and water. The poliovirus enters through the mouth, travels down the digestive track and is excreted in the stool. Millions of people come down with a very mild case of polio without even knowing it. The symptoms are quite common, like a mild case of the stomach flu. Those who get it build up antibodies that create a lifetime of immunity. But, in a very small number of cases, perhaps one in 200, the virus travels through the bloodstream, into the central nervous system, destroying the motor neurons that stimulate the muscle fibers to contract, and that causes paralysis. It can be a lifetime of paralysis, and if it affects your breathing mechanisms in the diaphragm (which is called bulbar polio) it can cause death.

Polio is a visual disease. Everyone my age can remember children in leg braces, on crutches, sitting in wheelchairs, or flat on their backs in terrifying iron lungs. The iron lung was for children who couldn't breathe on their own, whose diaphragms had been temporarily or permanently paralyzed. The iron lung had been created in the 1920s by a Harvard professor to assist gas workers who were overcome for short periods of time. But we had children who were put into iron lungs for days, months, sometimes years. There are cases today of children from the 1950s still living in iron lungs. No one at that time could have possibly imagined the moral, medical, and financial issues that would surround such long-term care.

Polio had been endemic in our world for many, many centuries. Yet for reasons that are still unclear it only became epidemic in the west, and particularly in the United States, early in the 20th century. There are many things about polio we will never fully understand. Once the vaccine became widely available after 1955 the questions surrounding it became moot because we now had a way of preventing the disease. For example, why did polio spread in the summer months? We really don't know. It appeared to affect more boys than girls. Was that true? Perhaps. The theory was that boys played harder than girls, thus when they encountered poliovirus, their immune system was compromised.

Most important, why did polio epidemics occur in the 20th century, and why mainly in the west? The best theory we have is that polio is a disease of cleanliness. In a cleaner, more antiseptic society, children are less likely to be exposed to the poliovirus at an early
age, when the infection was milder and maternal antibodies offered a temporary protection. Put simply, in this case, good hygiene brings risks as well as rewards.

I can remember my mother checking, literally, every week for polio symptoms. We had to wiggle our toes, we had to put our chin down to our chest, had to [bend our knees] and the like. The slightest cold, and particularly any complaint relating to stiffness in the muscles, would bring the doctor immediately.

Polio also came at a time when penicillin and other wonder drugs were doing away with bacterial infection. Indeed, there were many scientists predicting that the world would soon be free of infectious disease. This made polio all the worse. Arriving in full force at the very height of the post-World War II baby boom, it was viewed as the crack in the idyllic, middle-class picture window. We must remember that, despite all the new antibiotics, polio could not then be prevented or cured. There was no way for a parent to protect against it. Polio chose its victims at random. Every child was at risk.

The battle against polio would have an enormous impact on American society. Indeed, it would change the way that both philanthropy and medical research are conducted in the United States. And it began with the March of Dimes in the late 1930s. And, as some of you know, the founder of the March of Dimes was President Franklin Delano Roosevelt. At the advanced age of 39, from a well established aristocratic family, a big strapping fellow, FDR came down with a children's disease, infantile paralysis, in 1931. Why him? We don't know. He may have been unlucky. There also may have been factors that increased FDR's chances of getting polio. I'll go into them briefly.

FDR had been an Assistant Secretary of the Navy during World War I. He was very effective in this post, but he was also involved in a scandal involving homosexuality at a naval base in Rhode Island. It's a long story, but he was accused of employing spies to uncover a "homosexual plot" there. FDR had run for Vice President in 1920; it was a grueling election and he lost. After the election, he is hauled down to Washington in the brutal summer heat of 1921 and grilled mercilessly-and publicly-by a hostile Republican-led Congressional committee. Some suspect his immune system was compromised by this emotional trauma.

He then headed back to Campobello Island, off the coast of Maine, where he had a summer retreat, but on the way, he stopped at a Boy Scout jamboree in the Hudson Valley, north of New York City. The last photo we have of FDR walking unassisted-it's a very poignant picture-is with these boy scouts. It's very possible that's where he encountered poliovirus. He went on to Campobello Island and tried to drown his sorrows in frenetic physical activity for three or four days. At one point he fell off his yacht into the frigid Bay of Fundy. He spent that afternoon in a wet bathing suit, doing correspondence. The message here may be: listen to your mother; chilling, it appears, can be a dangerous thing.
When you add all these factors together—the political scandal, the emotional trauma, the trip to the boy scout camp, the frenetic activity after the virus entered his body—FDR may have been a vulnerable candidate for paralytic polio. What we do know is that he would spend the rest of his days searching for both a cure for polio and a vaccine to prevent it—neither of which happened in his lifetime.

FDR would go to Warm Springs, Georgia, which became a kind of second White House, where he tried every imaginable kind of therapy. But what he did—and this is far more important—was to set up the March of Dimes.

The March of Dimes is really the key to "the people's crusade" against polio. The first thing it did was to turn philanthropy on its head. Until the 1930s, if one wanted to create a charity in the United States, one approached a few rich people and convinced them to contribute several million dollars. What the March of Dimes did was to ask for small donations from millions of people. In other words, everyone could give something to stop this children's disease, and the dime became the symbol of that giving. I'm sure there are many people in the room who collected dimes, as I did, to end this horrible disease.

The March of Dimes used Madison Avenue public relations razzmatazz in ways that have never been done before. It is the March of Dimes that instituted the poster child, which is used by every charity today. Each year, beginning in the 1940s, there would be little smiling, blond child—boy or girl—in leg braces, on crutches, surrounded by striking rays of sunshine, saying "With your dimes, we will conquer polio."

It was the March of Dimes that used celebrities for the first time. Elvis Presley and Bing Crosby sang for polio. There would be gala fashion shows at the Waldorf Astoria, in which Grace Kelley would walk down the runway with the latest Dior fashions. Dozens of other cities would imitate this with mini fashion shows. Celebrities loved the publicity of being attached to the conquest of a children's disease. I have a picture in a book of then Vice-President Richard Nixon, in his suit, as always, pumping gas for polio.

Most effective—and enduring—was the Mothers March For Polio, a strategy used by every major charity today (with walks and runs and marches). One night each year, on the anniversary of FDR's birthday, the March of Dimes would mobilize tens of thousands of women to go door to door collecting for polio. The national slogan became "Turn Your Porch Light On," and the beauty of this slogan was that the volunteer knew exactly where to go. If the light was on, the family was ready to contribute. The March of Dimes raised hundreds of millions of dollars in the 1950s through this and other devices. Indeed, it raised more money than every other charity in the United States combined, with the exception of the American Red Cross.

Now, what did it do with the money? Well, some of it went back into advertising, as you would expect. But, funding was also used for rehabilitation, the long term care of patients, and a good chunk was used for medical research. This was a time when the federal and state funding for medical research was almost nonexistent. The March of
Dimes used this money to find a cure for polio, which never came, and for a successful polio vaccine, which arrived in 1955.

The March of Dimes brought together many of the best virologists, biologists, and epidemiologists in the United States. To create a successful vaccine, three problems had to be solved. First, how many types of poliovirus were there? This was vital, for a vaccine would have to contain every type in order to offer full protection. March of Dimes researchers tested poliovirus from all over the world. The process took a full year. It turned out there were three separate types.

Second, how did one produce enough safe poliovirus for use in a vaccine? A researcher named John Enders, who won the Nobel Prize in 1954, discovered that poliovirus could be successfully grown in nonnervous tissue, which was safe for use in humans. This guaranteed a plentiful supply of poliovirus for the coming vaccine.

Third, how did polio travel through the body? This was absolutely crucial, for the prevailing theory up until the late 1940s was that poliovirus entered the body through the nose, went to the brain, and then traveled directly into the central nervous system. If that were the case, if polio never entered the bloodstream, then a vaccine that produced antibodies in the blood would do no good against this particular disease.

One of the beauties of polio research, is that it included the best minds in the field, regardless of race, gender, or pedigree. The March of Dimes recruited scientists who were young, smart, aggressive, and ambitious. At a time when there was tremendous anti-Semitism in the medical community, it gave out the largest grants to two Jews, Jonas Salk at the University of Pittsburgh and Albert Sabin at the University of Cincinnati. At a time when there was enormous discrimination against women in the field of medical research, the March of Dimes subsidized the work of Dorothy Horstmann, at Yale, and Isabelle Morgan, at Johns Hopkins—each of whom proved indispensable in polio research.

Horstmann was the first researcher to discover that poliovirus does enter the bloodstream before it goes into the central nervous system. She was the one who found that a vaccine could work—a discovery of immense importance. Isabelle Morgan produced a polio vaccine—a killed virus vaccine—in the late 1940s, and it was quite successful. She was about to begin human testing; she was well ahead of Jonas Salk at this point. Then, as happened with so many women of that era—and many today—Morgan made a choice. In her late thirties, she decided she would get married and start a family; she left polio research forever. I believe that if she had stayed the course, remaining at John Hopkins which was well funded and filled with brilliant researchers, we would be talking today about the Morgan vaccine rather than the Salk vaccine. She clearly blazed the path that Jonas Salk took to completion.

There would be no lone wolves in this research effort. The March of Dimes clearly encouraged competition—with Salk working on a killed virus vaccine while Sabin worked
on a live-virus vaccine—but it also demanded cooperation. All information would be pooled.

The March of Dimes was the first organization to give out long-term grants to researchers. Five years was the norm. The research was carefully monitored by a central committee dominated by top scientists in the field. Some grants were pulled after a year; others were fully funded and renewed.

It was the March of Dimes that originated the notion of indirect costs. What does this mean? One of the first grants, for $50,000, went to John Enders at Harvard. Enders was thrilled, but Harvard turned it down, explaining: "Who's going to pay for the supplies and the security and the heat and the lighting and the monkeys? We can't do this." So, in addition to funding the grant, the March of Dimes also paid for the indirect costs of the grant. Medical research in universities today would be hard pressed to survive without these indirect costs. Thus, as the March of Dimes revolutionized philanthropy in the United States, it also revolutionized medical research.

In 1954, with little government interference or cooperation, the March of Dimes produced the largest public health experiment in American history. Well more than a million children were lined up and given either the Salk polio vaccine or a look-alike placebo. Nobody could be certain whether the vaccine worked, or whether it was even safe; but it tells you something about the enormous fear of polio in this era that parents rushed to line up their children to take part in that experiment. My mother was the type who accounted for every aspirin that we took in our house, yet she pushed me right into the polio line to get my shots. Now, my mother was a very tribal woman and I always felt that her thinking was, "We're Jewish. Salk's Jewish. How bad can it be?"

[Laughter]

This was a double blind experiment, meaning that neither the child getting the vaccine, nor the doctor or nurse giving the vaccine knew whether the child was getting the real vaccine or the look-alike placebo. Jonas Salk dramatically and publicly opposed a double blind study because he was confident that his vaccine worked and he felt, therefore, that it would unconscionable to deny children the real vaccine in the middle of polio season, when 50,000 kids a year were contracting the disease. But the scientific community demanded a double-blind study to ensure full confidence in the results, and the March of Dimes—and eventually Salk himself—went along.

This was in an age when computers were still new and primitive. All of this material—three separate polio shots involving almost 2 million children—had to be coded and analyzed by a staff of evaluators at the University of Michigan. It takes a full year, but in April of 1955, at a dramatic press conference on the Michigan campus, Dr. Thomas Francis, the lead evaluator, declared the Salk vaccine to be safe, potent, and effective. A national celebration began. Schools closed, fire whistles went off, and church bells rang. It was as if a war had ended, and in fact a war had ended, the war against polio.
Most amazing, it was all done voluntarily by millions upon millions of Americans who gave their time, their money, and their children to this cause. The Salk vaccine, as you know, had a dramatic impact on lowering polio rates in the United States. Unfortunately, I don't have time to go into the Sabin vaccine, the live-virus vaccine that competed with Salk's.

Sabin believed it was far more effective—as did most members of the research community. Sabin and Salk had a wildly competitive relationship. Sabin was forced to go the Soviet Union to test his vaccine because so many children had already been given the Salk vaccine in the United States. Sabin later said that there's just no better place than communist Russia to test.

[Laughter]

Everybody shows up and lines up. There are no laggards there. His vaccine proved to be extremely effective, and indeed, by the 1960s, it took over as the vaccine of choice in the United States. Because it creates a natural infection in the body, it produces stronger immunity. It is given through the mouth, rather than through injection, so it's simpler and cheaper to use. The key problem with the Sabin vaccine is that one in several million children who take it, or a perhaps diaper-changing parent, will actually come down with polio from the vaccine itself. So, you might get down to 15 cases of polio in the United States each year, but you'll never get below that level, because there'll always be a tiny number of vaccine-induced cases. As some of you may know, we have now gone back to the using the Salk vaccine in the United States for just that reason—so that all cases of polio can be eliminated.

A final word about the March of Dimes: There was some criticism that it over-hyped the perils of polio in the post-World War II America. By this I mean that the disease, even at its worst, was never a raging epidemic in comparison to other serious childhood diseases such as cancer. There were a maximum of 50,000 cases and maybe 5,000 deaths a year at the height of the polio epidemics in the 1950s. Still, the March of Dimes raised the lion's share of charitable money, and it angrily refused to join the United Way or the Communist Chest, saying, essentially, "We have our mission, which involves both providing a lifetime of care for polio patients and finding a way to end the disease." It also said, in effect, "We have made a compact with the American people: you give us your money and we will find you a vaccine." So, there really are two ways of looking at it. The March of Dimes did, indeed, take a lion's share of the charity dollar in this era, but—far more important—it made good on its promise to forever end the scourge of polio in the United States.

The March of Dimes also created the first celebrity scientist in Jonas Salk. Salk became Sir Galahad in the white lab coat. His picture adorned time magazine. He went along with it, I suspect, because he understood it was good for the polio crusade. But, it also made him an outcast in the scientific community, and that is really remarkable. Albert Sabin was the scientist's scientist and Jonas Salk was the people's scientist. Jonas Salk is
the only major polio researcher never to be inducted into the National Academy of Sciences.

It's sad when you think about it, but he was black-balled by Albert Sabin and others who claimed that he had never done anything original. Sabin actually said of Salk's vaccine, "I could go into the kitchen and do what that guy did." The competition between them was so fierce that neither won a Nobel Prize, but Jonas Salk once said, "I really don't need it because everyone believes I did win it," and there is, I think some truth in that.

[Laughter]

Finally, it was through the March of Dimes, I think, that we entered the modern era of extraordinarily focused medical research. The March of Dimes was really the first organization that set up a committee of virologists who determined what had to be done and the steps that had to be taken to do it. It found the best people, gave them the best facilities and lavish funding, and paid for the indirect research costs. In turn, it demanded cooperation as well as competition, and in the end its efforts gave us a vaccine—actually two vaccines—that have all but eradicated polio in the United States today. The crusade against polio in America took place before the federal government became deeply involved with protocols and research money and regulation. Some of you may know that much of the earlier polio testing was done on children in state facilities, without little heed to contemporary standards regarding informed consent. It was a very different time.

But the real message of the polio crusade, I think, is the message of volunteerism. Millions of people gave their time, their money, and yes, even their children, to an extraordinarily worthy cause. Their unity reflected the steady faith of post-World War II American society in the progress of medicine and technology and the certainty of positive change. The fear of polio no longer haunts America, and, God willing, it will soon be gone from the world. As we look back today, that is a lesson well worth remembering.

Thank you very much.

[Applause]

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**Q&A with David Oshinsky, PhD**

D.A. Henderson: Monica, we have time for some questions, do we? How much? Ten minutes for questions, and then there will be a break for fifteen minutes where you may go out and look for the book. So questions now.
David Oshinsky: Any Questions? Yes, sir.

Joe: Joe Dudley, EAI Corporation. It's Interesting to have Dr. Henderson here, because this question crosses both lines. We saw a situation a couple years ago where we thought that polio was isolated to a small area in one country on the African continent, and on the horizon was the possibility that polio could be dealt with as small pox had been dealt with. And we've now seen polio go from Nigeria westward across West Africa, eastward to India and Indonesia.

And the interesting thing for this conference is that this was tied to a lack of communication with a cultural community that had a great fear of outside intervention and a propaganda campaign that snowballed into a popular resistance. Originally the popular resistance was seen as a local phenomenon, until some people went to the Hajj, and polio is halfway around the world once again.

Number one, do you think we can get the genie back in the bottle again? And number two, do you think we can make this lesson learned, so that these same contradictions don't interfere with other future epidemics. I think one thing we forget is that many people in many parts of the world don't believe in the pathogen-disease-illness syndrome.

D.A. Henderson: I think we want to leave time for other questions.

D.A. Henderson: Well there was an article in Science just last week, which I think summarizes it, and there are differences of opinion as to some who still think it can be reached and there are some who, at this point, feel the obstacles are too great. I am quoted as thinking it is not possible to eradicate it and what we need to do is have a long term control program.

Sarah: Sarah Landry from GlaxoSmithKline. I was wondering—the Cutter incident—how that was handled? And what I perceive from what I have read to be a fairly—what's the word I'm looking for—the public did not seem to have lost confidence in vaccines as a result of that. I'm wondering what lessons we can draw from that experience now, what
do you attribute that to, and is there anything we can do as we try to reinforce the public confidence in vaccines in this country?

**Dr. Henderson:** OK, as some of you may know, in 1954 after the vaccine was determined to be successful, the March of Dimes had already paid a number of drug companies to produce large amounts of the vaccine and the government immediately agreed to this and these companies began producing it. One of the companies, Cutter Labs of Berkeley California, was not following protocols carefully, and even though it was a killed-virus vaccine they were not killing the virus as well as the protocols demanded. There was live polio virus in their vaccine and a number of kids came down with polio and died. And so right after the Jonas Salk vaccine is declared successful and there's a victory, suddenly there's vaccine out there that is very dangerous.

What the government does—and if there is a message, it was: what the government did very quickly with the Public Health Service was to take all of the vaccine off the market temporarily. All Cutter vaccine was recalled, and Cutter never made polio vaccine again.

What they did was send epidemiologists into the field and found out very quickly what the problem was, it was Cutter vaccine, they allowed other companies who were producing safe vaccine back on the market and what was interesting was that if there is a message here, the government was so honest with the people, both in taking the vaccine off the market very quickly, finding the problem, and dealing with the problem, that when the vaccine went back on the market, people began putting their kids forward to use it again. So it seems to me that the message there is sunshine and openness. It is one of the great stories, and it's in my book, of sort of how quickly the Public Health Service really honed in on Cutter and found out what the problem was. So, I think that is the answer. There is an interesting book out by Paul Offit, who is a very well known virologist, on the Cutter incident, just came out. Paul is also, as a doctor, very interested in the litigation aspects of what came out of Cutter as well, which are quite controversial.

**Dr Henderson:** Yes?

**Woman 1:** When we look at the Avian Bird Flu, and there just seems to be a lot of hysteria already in the media for something that might not happen. I was a little girl in 1959 and I still remember the hysteria about polio, places we couldn't swim because we'd get it. I didn't even know what it was, but literally terrified I would fall into the marsh. Did the March of Dimes help the hysteria, did it, in some ways, make it worse, and are there some public relations lessons we can learn from that, for any pandemic flu we might face?

**Dr. Henderson:** That's a hard question to answer. The March of Dimes' role, I'm a big supporter of the March of Dimes, and of Rotary international, which has taken on the fight against polio as you know. I think what the March of Dimes did was, on the one hand, it did scare people, I think, beyond the scope of polio. In other words, given the numbers, what you could say is that they were doing this as a way of raising money and that is true. On the other hand, they let people know what the precautions were, you
know, if there were symptoms, go to a doctor. If the child does have polio they set up regional centers to deal with it.

On that level, I think they were extremely professional: The difference with Avian Flu is that, if it comes, you're talking about a pandemic that will be much greater and wider than anything related to polio. I mean the worst case scenario could be the flu of 1918-1919. My sense is that the lesson here would be, certainly, to educate people, and to make certain that the government is actually following procedures that will try to minimize it when it comes and have effective ways of dealing with it. The March of Dimes was a very different kind of operation. I mean, their operation was to protect people against polio, but it was also in raising awareness to raise money as well. Those went hand in hand.

**David Oshinsky:** Any other questions? Well, thank you very much I really appreciated being here.

**D.A. Henderson:** We are grateful indeed. Now let me just say a word about the book. This is a page-turner. There's no question about it. There're more interesting stories in that book than you could possibly imagine and in fact there's one for the Canadians, which most people don't know, and that is when they're trying to make the vaccine for the big field trials, the only company that really knew how to do this and had worked it out was the Knott laboratories in Canada.

And so they made all of the vaccine in bulk in Canada, and the March of Dimes was so concerned that it had to be a hush-hush operation. They wouldn't let it be publicized that this was a Canadian-produced product. But it was Canadian-Produced, shipped over, bottled in the United States, and it wasn't until very much later that anyone found out that the Canadians had played a very important role in the vaccine.

[Applause]

**Dr. Henderson:** The one other story that I thought would be revealing and I'll mention very briefly was that Jonas Salk, as a young man in the 1930's coming from New York city, was involved in sort of Left Wing causes, which was very common in the 1930's. In the 1940's, Jonas Salk needed a security clearance, an FBI check, to work for various parts of the government and to get his research money, and they did two full-field FBI investigations on Salk that are hundreds of pages long. And had it been up to J. Edgar Hoover and the FBI, that would have been the end of this anonymous researcher, who was not known at all at this time.

Amazingly, and just looking at the FBI file you cannot be sure, he was cleared by the surgeon general. Had he not been cleared, there would have been a vaccine, but Jonas Salk would not have played a role in it. What is extraordinary is that in 1955, when Salk is invited to the White House with his family, everybody is cheering. Eisenhower thinks this is the best thing for American foreign policy; we're going to give the vaccine to the
world. A letter arrives from J. Edgar Hoover: "I wouldn't allow this Lefty in the White House." It's an interesting story.

**Dr Henderson:** So, as I say, it is a page turner, and you will love it. So, you can get the books outside, I think we've got fifteen minutes to 1:30 and David is prepared to sign at that point.

Thank you all very much, thank you David.

[Applause]

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**Eric Toner, MD**

**What Would a Modern-Day Flu Pandemic Look Like?**

**Monica Schoch-Spana:**

It's a real pleasure to introduce my colleague, Dr. Eric Toner, who is going to talk to us today about what a modern-day flu pandemic will look like. Eric has 23 years of experience in emergency medicine, 20 of which have been specifically in disaster medicine. It is my pleasure to welcome Eric to the table. Thank you.

[Applause]

**Eric Toner:**

Thank you, Monica. Well, this is my topic-what would a modern-day flu pandemic look like, and I think I need to change the title to what might a modern-day flu pandemic look like because, I'll confess to you, I don't know. I need to give you a disclaimer, as does everybody else who talks about this.

No one really knows what a pandemic would look like. Everything that we say in this topic is based on the three pandemics of the twentieth century: 1918, 1957 and 1968. Three is not a very big sample size [from] which to draw many conclusions, particularly because the information we have about 1918 is quite fragmentary. Remember, this was before the age of virology, so a lot of assumptions have been made. But, having given that disclaimer, I will go forward.

The one thing we can say about pandemics-it certainly has been true about the last three-is they happen fast. This is a map of the United States in 1957, in August [note: refers to slide images]. The white represents states that were not affected by influenza, in pink are states in which ten percent of the counties were reporting cases, and in red are states in which fifty percent of the counties were reporting influenza. This is August. This is mid September. Two weeks later...two weeks after that...two weeks after that.
From the beginning of the outbreak of the pandemic in 1957 until it involved every state was approximately two months. The same thing happened in 1918, and the same thing happened in 1968. I would also point out, as did D.A. [Henderson] earlier, this started in August. In 1918, it started in September—not typical months for flu.

How bad would this be? These are the HHS's planning assumptions for influenza. They used two models: a moderate based on the 1968 pandemic, and a severe model based on the 1918 pandemic. Both models assume that thirty percent of the population will become infected, and half of those individuals will become sick and need medical care. The big difference is in the assumptions with regard to hospitalizations; there is roughly a tenfold difference. Derived from that is the number of people needing ICU care and the number of deaths.

Those numbers really don't do you much good if you are trying to prepare a hospital or community. What you really need to do is know how many cases there will be in your community, because influenza will travel across the country in a moving wave and go through each community in a period of about two months. Using FluSurge which is a CDC program for modeling influenza in a community, we've taken the HHS planning assumptions, and what we find is [that] in the mild or moderate scenario, 19 percent of existing hospital beds would be occupied by flu patients at the peak, 46 percent of the ICU beds would be occupied, and 20 percent of the ventilators would be occupied. This doesn't look so bad, except all of these resources are normally fully occupied on any given day, so where are we going to put the other patients?

The situation is very different if you look at the severe scenario. In the severe scenario (which is the 1918 scenario), 191 percent of regular hospital beds would be occupied by flu patients alone, 461 percent of ICU beds would be occupied by flu patients alone and 200 percent, basically, of the number of ventilators would be in use by flu patients. Obviously, planning for this is much more difficult. This is the HHS worst-case scenario. I would point out that there is no biological reason to think that this is the worst-case scenario—this is just the worst that we have experienced.

Is it realistic to expect that public health can prevent such a scenario? Let's talk about how you stop an epidemic. First, there are vaccines, and then there are antimicrobials. In this case antivirals are to be used either prophylactically or for treatment; and thirdly, there are disease containment efforts. Vaccines-flu is constantly changing. Therefore, you can't produce a vaccine in advance of a pandemic, you can't predict what the strain will be, [and] you can't stockpile. There is very little manufacturing capacity in the world for influenza vaccine, and we have a very old and slow production technology. Lastly, once a vaccine is produced, we can't be sure of how effective it will be—such [is] the problem we face now with the current trial vaccine.

In regards to antivirals, we have a limited supply, and again, a limited production capacity, such that prophylaxis on a large-scale is not practical—there are just not enough drugs. Resistance develops rapidly with Amantadine, not quite so rapidly with Tamiflu, but it does develop. The dosage and duration of treatment needed varies from strain to
strain, so all of our planning right now is based on using Tamiflu in its current dosage, which is used for seasonal flu. It appears that for H5N1 that dosage is insufficient; you would probably need twice the dose for twice the period of time. Timed treatment is critical; ideally you want to start antivirals within hours of the onset of symptoms. If you delay more than two days, it probably has no value at all. We have to have systems in place to be able to deliver these drugs to the right people in a short period of time.

Disease containment...A lot of features go into disease containment. First of all, isolate the sick—that's a no-brainer. Identify and maybe quarantine those who are exposed, perhaps a geographic quarantine. Travel restrictions. Social distancing such as closing schools, canceling gatherings, avoiding crowds and staying three feet away from each other. Infection control [such as] restroom etiquette, hand washing, [and] using masks, gowns and gloves.

There are problems with flu. It has a very short incubation period, two days on average, which gives you no time to trace contacts and implement quarantine. In seasonal flu, at least—and we think in the previous pandemics—there is both pre-symptomatic and asymptomatic spread. Perhaps as much as 50 percent of people who spread flu don’t have significant symptoms. This means isolation could only be partially effective at best, and you can’t identify all of the people who are spreading the disease. In addition, there is a very short time between generations, perhaps just 2-3 days, which means that it spreads very rapidly and there is no time to implement geographic quarantine, for example. One infected flu patient could become a million flu infected patients in 60 days.

Is it realistic to expect that public health interventions will prevent the kinds of scenarios that we have talked about? Simple answer—it can’t be stopped. At best, public health measures can slow the virus, but even this isn’t proven. All of the measures that we have talked about to slow a pandemic have economic and societal costs, which may exceed their benefits.

Is it realistic to expect that medical interventions will thwart the impact of a pandemic strain? In an ideal world, there would be unlimited surge capacity in the healthcare system, and all flu patients would be treated with normal health care standards, and healthcare would go on unaffected. But, let’s take a look at the U.S. healthcare system. Thirty percent of U.S. hospitals are losing money, and of those that are profitable, they have an operating margin of about 1.9 percent. There are 45 million uninsured, and $25 billion a year in uncompensated care. We have shortages of healthcare workers across the board. Half of our emergency departments are at or over capacity, and turning away patients because there are not enough inpatient beds.

Maybe the federal government can come in and help bail out the health care system? This is what Secretary Leavitt says about that, "Any community that fails to prepare with the idea that somehow in the end the central government will be able to rescue them will find out that they are tragically wrong." He has said it in 50 different states over the
course of the last two months-they're not coming, they can't be there, [and] you're on your own.

What are the most likely ethical and practical dilemmas that communities will face in trying to prevent additional infections and care for a large number of sick people during a pandemic? There are many, and we'll just list a few. First of all, how to allocate the scarce resources of vaccine and antivirals? How to allocate the scarce life saving medical resources, such as ventilators? If you only have one quarter of a number of ICU beds, and one-half the number of ventilators that you need, how do you decide who is going to get them? How do you ensure that all the hospitals in a given community are providing the same level of healthcare, that is, that they are all using similar processes to make these decisions? How do you make decisions about what other forms of healthcare aren't going to be provided during a pandemic? How do you enforce voluntary-or otherwise-isolation and quarantine?

Thank you....

Q&A Session

Arrietta Chakos:
I'm Arrietta Chakos, with the city of Berkeley, California. I have to say that your comments were very, very sobering. I'm sure we'll learn more from the panel now, but I was interested to hear earlier Dr. Henderson saying that he felt that quarantine, as a tactic, might not be as effective. I noticed that you do speak about that when you talk about using vaccines prophylactically, looking at antimicrobial use, and then public health enforcement. What practical measures can we look to in the communities if social isolation might be a step, but quarantine on a large-scale basis might be impossible?

Eric Toner:
Well, I mentioned quarantine because it is in the national plans, and I think it is something we need to deal with from a scientific/public health standpoint. Like Dr. Henderson, I don't believe that quarantine is likely to be that useful. It may be of value to encourage people who have been exposed to voluntarily stay out of circulation if they can. But quarantine in the way that it is envisioned by many-particularly quarantine in which there is a governmental role in enforcement-is probably counterproductive. And certainly, geographic quarantine which is what many people think about when we talk about quarantine probably has no scientific basis.

Roundtable I

Who Receives the Limited Doses of Pandemic Flu Vaccine?

An Exercise in Shared Decision-Making
Peter Singer (moderator):

My name is Peter Singer. I am the moderator of this afternoon's session. I've got two qualifications to do that. One is in November our center released a set of ethical guidelines for pandemic influenza planning—the University of Toronto Center for Bioethics. The second is that I'm a frustrated talk show host. I want to be reborn as a talk show host, so in about an hour we'll see whether that is a realistic aspiration. I just want to start by introducing the panelists, and then I'll do just sixty seconds of framing. We'll get right into a scenario and we'll get moving.

I'll just go from right to left: This is Nelson Ortega who is executive director of Centro de la Comunidad in Baltimore, Maryland. And this is Sarah Landry, and Sarah is the director of public policy for vaccines for GlaxoSmithKline, but formerly [she] was the associate director of policy and program operations for the National Vaccine Office in the U.S. Department of Health and Human Services. This is Carol Jordan. Carol is the director of communicable disease and epidemiology at the Montgomery County Department of Health and Human Services in Maryland. This is Dan Hanfling. Dan is the director of emergency management and disaster medicine for the Inova Health System in Falls Church, Virginia. Peter Gudaitis is the executive director and CEO of New York Disaster Interfaith Services, and Maggie Fox is a health and science correspondent for Reuters. So that's our panel. A great variety of expertise.

We're going today on the "twenty-twenty-twenty plan." For about twenty minutes we're going to simulate what a public engagement exercise in relationship to allocation of vaccines could look like. We're going to use that as a model. I'm going to focus narrowly, as I'll say in a second, not too narrowly, but I am going to focus a little bit on the last week's, or two week's ago issue of whether to treat the healthy folks or treat the people who are sick—just to help focus it because we only have twenty minutes. But, the real purpose behind that first twenty minutes is to simulate what one could do in real time—as an issue comes up in the media—to engage people in discussion. Just imagine the first twenty minutes is [a] webcast public forum for Canadians moderated by Peter Mansbridge. For people in the United States, moderated by Neil Cavuto; I heard him the other day.

So, that's twenty minutes of simulation. The next twenty minutes, we'll say, what does that twenty minutes look like in terms of public engagement around this question we're focusing on—namely, allocation of vaccines? Is that the best way to do it? Not so much why you would like to engage the public, because we covered a lot of that this morning, but how you would do it. I mean, is this idea of a panel and web casting the way to go or [some] of the other things [that] we heard [about] this morning? And we'll ask our panelists that.

The last twenty minutes we'll get into a question and answer [session with] the audience, more broadly, on either the scenario and the issues there—and we might do a little interaction and voting on the first twenty minutes, or on this broader question of
public engagement around vaccine allocation as the specific example with an emphasis on "how to." Sound okay? Any questions before we go ahead?

Peter Singer (moderator):
Great. I'll just start by reading a scenario and kicking off the first 20 minutes. This is about who receives limited doses of pandemic flu vaccine.

The scenario goes like this: In September (and we're really talking about this year, September 2006), the novel strain of H5N1 virus begins to spread rapidly throughout several Asian countries, with increased and sustained person-to-person transmission. In response, on September 20th, 2006, the World Health Organization officially declares the onset of an influenza pandemic. In late September, the CDC informs state health departments that H5N1 vaccine will not be available until March 2007 (about six months later) despite emergency efforts to produce vaccine against the novel strain.

CDC will distribute vaccine through the Strategic National Stockpile to state health departments in batches as it is produced and according to the state's population. State health agencies expect to receive enough doses to vaccinate 20 percent of their populations initially, with comparable portions coming each month thereafter, starting in March 2007–20 percent per month in terms of an up-scaling.

With this knowledge, your city's health agency begins to review and update its plans for distributing the first and subsequent batches of the vaccine. At the health officer's briefing for flu vaccine planning, the mayor wonders aloud which 20 percent of the city's residents get to stand in line first for the flu vaccine shipment and how everyone else will live with that decision. The health officer explains that broad federal guidelines do outline priority categories, but she estimates that the city residents who populate the top priority groups far exceed the initial allotments of vaccine.

Peter Singer (moderator):
With that, Sarah, I think the question that is on many people's minds—before we zero in on the priority and allocation issues—is why is there scarcity? Why do we have to prioritize in the first place? Why can't you guys just make enough vaccine a month later? Forget about this 20 percent a month, six months later! What's the problem there?

Sarah Landry:
The assumption is that vaccines are like cars and you just flip a switch and you pull things off a conveyor belt. Vaccines are made with living organisms, and they're fickle. We're working with strains that don't always grow well in [inaudible]. The influenza virus is constantly changing, which is part of the reason you have to have a new vaccine produced every year. We're not in a position where we can stockpile excess vaccine, have it ready to go and send it out at a moment's notice.

I think there's another issue here with pandemic flu, which is, you're trying to balance having supplies available, but making sure they closely match what will emerge as the pandemic flu strain. You're hedging your bet. What you see the federal government
doing right now is stockpiling pandemic-like vaccines, but there’s no way of knowing whether or not the vaccines that have been stockpiled will, in fact, be effective if a pandemic virus emerges.

I think the bottom line is that vaccines are complicated products to make and that they do require time to be produced. You can’t stockpile and have everything waiting in a cabinet waiting to go. It takes time to grow the viruses, fill and finish into a vaccine and make sure it’s safe.

Peter Singer (moderator):
Sarah, this is a real scenario of scarcity. The folks who wrote this didn't make things up and things will really be scarce.

Carol, you may be the person closest to this hypothetical health officer in this scenario. It says here, that you’re talking about this vaccine—which 20 percent of the residents, the mayor is helpfully wondering aloud, "Who's going to get it?"-and the health officer explains that broad federal guidelines do outline priority categories, but you think the top priority groups exceed those guidelines. Tell us a bit, if you can, about those federal guidelines and who would actually get this vaccine according to those guidelines.

Carol Jordan:
Right. The federal guidelines are spelled out really clearly. I believe it's the vaccine manufacturers first and the people who deliver the vaccine, then the health care workers and so forth and then the elderly people that are ill. A lot of the controversy about this is the issue of the children, because healthy children fall way down on the list. I think that's one of the hardest things for us all to take, even though a lot of time-as Roger Bernier spoke about earlier today-we spent a lot of time dealing [with this issue in] the PEPPPI Project and really struggling over that particular issue. I know that our Canadian friends did the same thing. It was not an easy priority list to come about.

But at this point of time, in a local government situation, I'd be getting really nervous, because I would know that it would almost be the same as the shortage we had in the '04 -'05 normal flu season. Only the panic and the fear and the dread would be a hundred times multiplied. There's no right answer here about how to approach this.

I know [that] in the '04 -'05 season what we did in our particular county, which has a million people, is we tried a flu lottery system—that is just is one way to approach the situation—about two years ago. I know it was not perfect. In our county, in the public health sector, we normally give out about four or five thousand dosages a year, and the private sector does pretty much all the rest. When we opened up the lines for the flu lottery, within two days, 22,000 people called in and they were all in the "high-risk" CDC categories. So, it was a big dilemma. At that moment, we had 800 dosages to give out to 22,000 people. For many people it was the first time they'd ever gotten a flu vaccine, but because of the shortages and the scare, they really wanted to get it.
I think we would be faced, in this situation you're talking about right now, with making some really difficult decisions about how to give out that limited resource to a much larger population of people that fall into the initial high risk categories, and basically doing the best we can with that situation. It pretty much comes down to first-come first-serve and having a call-in to make appointments or some kind of flu lottery system, whether it’s a weighted lottery or a regular kind of lottery system. I'll say more, but I'll stop there.

Peter Singer (moderator):
Terrific, thank you, Carol. I have those National Vaccine Advisory Committee guidelines here.

Maggie, let me ask you this, because it's a way to frame it, and actually the U.S. and Canadian guidelines are quite similar, for the Canadian content folks in the audience. Maggie, you're sitting there minding your own business on May the 10th, or May the 9th, in your Reuters office, and along comes this science article by a couple of bioethicists at the NIH. You write this article put out by Reuters, "Bird flu rationing proposal favors youth." You write about this in your article—everybody agrees—we heard this from the PEPPPI guys too—that the "continuity of society" people go first. Most people d the healthcare workers, the vaccine producers, the critical infrastructure, the first responders, etc.

Both the existing U.S. and Canadian guidelines then say you go to vulnerable people next. Older people with a couple of health conditions, people who have been admitted with pneumonia, essentially people who are at high risk of dying; that's where you go next. May 10th, you're sitting there and this thing comes along and it says—what? Can you just explain that and pick up the story from there?

Maggie Fox:
Actually, I got it in under embargo, so this was before May 10th. But I read the article and they're making the argument that, in fact, in the case of a pandemic, you don't necessarily want to go to the older people. You want to save the people that have the most valuable life years left, which they argue would be people who have actually invested some time in life, but still have a lot of life to live. This works out to be people 14 to 25—and would be very controversial. They go on to make the argument that young children haven't lived enough yet to have invested anything in their life, old people had their shot at it and these are the people that have the most to contribute to society, and it's the most efficient use of the scarce resources that they have.

Peter Singer (moderator):
So, on May 11th, you have Maggie's article and many, many other articles from all around the world saying, "You know what? Those U.S. and Canadian guidelines got it wrong!" The people- actually the 180 million people in priority group four that the U.S. guidelines put at the bottom of the list—should actually be second according to this article.
Dan, let me just check something with you before we go on. Part of the reason that the vulnerable, high risk groups are next (after the first responders, health care workers, etc) is because we think we can save lives by vaccinating those folks. But, some people say that the 1918 pandemic actually hit the 13 to 40 year olds that Zeke is writing about. I just want to check out [something]...are we really saving more lives by vaccinating the vulnerable 25 million or so people first?

**Dan Hanfling:**
It is a difficult question to answer, obviously, because it really hits at the ethical issues of what is a life, whose life is worth what, and is one life worth more than another? I can tell you that from the perspective of healthcare clinicians-I think there are many in this room that would echo this sentiment-we are spending an awful lot of money at the very end of life. It raises the question as to whether that really is the appropriate allocation of what already are scarce resources in the delivery of day-to-day healthcare-aside from this potential scenario of pandemic influenza or some other emerging infectious disease.

It is actually with great interest that I read this article and the commentary about this proposal because it begins to frame the question of relative values of life, and important in that is the engagement of healthcare professionals who do dabble at that very border of making some of those decisions.

**Peter Singer (moderator):**
Sarah, you're trying to get in here and we'll let you go now. But, I'm still wondering, even if you assume everyone's life is of equal value, is it true, in your opinion, that someone who gets flu in a pandemic in the 13 to 40 age group is actually less likely to die than someone who gets the flu in the-you'd think that's true...

**Dan Hanfling:**
You know, there are a lot of scientific reasons going back to 1918-1919 that can explain why the relatively young population was at much greater risk, and it had to do with immune modulation and the effects of one's own immune system in responding to the virus. Again, as Eric [Toner] said earlier, what might pandemic influenza look like? We don't know. But, certainly based on the 1918-1919 model, there is some reason to believe that [younger] age group may be more adversely affected, so maybe that should be the target of counter-measures.

**Peter Singer (moderator):**
Sarah, fire away.

**Sarah Landry:**
I think one of the things that we haven't talked about and [that] needs to be factored into this equation, is the effectiveness of the vaccine in different populations. I think one of the other considerations that needs to be explored-actually in the PEPPPI dialogue we did spend quite a lot of time talking about this-is the fact that the vaccine does not work as well in the elderly population. From an ethical perspective, does it make sense to use something that doesn't work as effectively in a portion of the population versus
spreading it out across more members of the [other] parts of the population? I just want to throw that out as another thing we need to consider.

**Peter Singer (moderator):**
But just to be clear, the PEPPPI guys rejected Zeke's proposal in the sense that they were going for the vulnerable people second, even to the point that they were cutting down on the first group, so they could get more of the vulnerable people. There's a pretty good consensus that those 13 to 40 year olds don't go next, right?

**Sarah Landry:**
I think we've had some assumptions that we were working under up front—that issue did come up. But, you're right, [about?] the end of the discussion.

...[NOTE: portion of roundtable not transcribed at participant's request]...

**Peter Singer (moderator):**
Everyone agrees pretty well-in all the media stuff and about Zeke's article that elicited this—that everyone's okay with health workers, first responders, critical infrastructure, vaccine, [etc., coming first]. Pretty well there's consensus.

The real question is who comes last, and who comes next, and actually who comes last, which is more to the point, which is why Sarah is laughing and she's absolutely right.

So Peter, what would the folks having interfaith dialogue in the New York Disaster Interfaith Services think about the women and children last idea that Zeke promoted?

**Peter Gudaitis:**
I want the other question.

[Laughter].

**Peter Gudaitis:**
I think one thing that this chart, if you will, doesn't take into consideration at face value is the cultural implications. Will the diverse communities of New York City accept these norms versus the ones they brought with them from the rest of the world, or from their own indigenous cultures?

When you look at communities that have faced genocide—like the Jewish communities or the Native American communities—where this sacrifice for youth is a higher value than anything else, to perpetuate the race. When you have faith traditions that have come from various parts of the world that don't value these priorities, then how do you get that population to accept this system? I'm not sure that you can.

The debate depends on so many unknowns as well: What is the critical need in the community in terms of the distributions of services in a city that is dependent on mass transportation and not individual transportation? Our population [in NYC] requires
subways, buses. There are very few cars, although it doesn't seem like it when you visit. How is the population going to move around? "Critical personnel" becomes many other things other than the medical community. There are many unknowns, and until the pandemic is understood better, it is very difficult to make these decisions in advance.

I don't think New Yorkers, typically, are going to accept somebody else's edict about how they're going to live their lives. I don't really think it's as simple as throwing a chart up and saying, "This has all been thought through, the government has decided, and this is what it's going to do," because, frankly, nobody really trusts the government at the moment, given its enormous failures in the humanitarian aid process in the past several years since 9/11.

**Peter Singer (moderator):**
Peter, you raised a number of very interesting points: the different cultural histories of people, the decision making in advance, the trust factor. I want to zero in on those in a minute. Remember, in our second 20-minute part of the show, we're going to focus on how much advanced public involvement would actually help clarify priorities in this scenario, and you've touched on exactly where we want to go.

Before we go there, I just want to bring closure to this first 20 minutes in the following way. Having run a bioethics center for 10 years, you know what my favorite scene in a movie is, right? It's Yul Brenner [from] the King and I [who says]-"on the one hand, on the other hand"-people must be familiar with that scene. I just want to pin you all down. Before we close this part, and really reflect on what the potential benefit of a discussion like this in the wake of a paper-like that Science paper might be-to revisit the planning priorities of U.S. and Canadian federal governments. Let's just pin you down a little bit.

Everyone, or most people agree, Maggie, with the first responders, the health care workers, the critical infrastructure, etc., first. There is some discussion about how many and who exactly they are. The question now-in the wake of this paper that you wrote so beautifully about-is who goes next? Is it the 150 or so million Americans that are 13 to 40 and completely healthy on this life cycle ideal? Or, is it the 30 million or so-and you wouldn't even get them all in the first month-who are vulnerable, sick, chronically ill, 65 and over, and have more than one or two health conditions?

Who do you think should go next and why? Do you think those federal guidelines should be revisited? From all that you've heard from interviewing on your article and so on, where did you end up on this issue?

**Maggie Fox:**
You're asking me to express an opinion. As a journalist who writes on this matter, I have no opinion. One question that I would really like to address as a journalist who is writing about this is the fact that our society seems to have made this decision, and people have made it on their own.
Every year, 36,000 people die of flu and the vast majority of them are over 60. We've already made that decision, these people have made the decision for themselves, [and] our society accepts it. "They're old, something's going to take them, [and] it may as well be flu." Nobody ever says that, nobody ever comes out and says that. And Katrina also illustrated that. Who were the people who were left behind? I think society sometimes doesn't make the decisions out loud, but they're quietly made by default. This may occur in this situation as well.

I can tell you as a mother of a five year old—I don't fall into any of the categories and neither does she—there was a bitter discussion in our newsroom about the priority groups.

Peter Singer (moderator):
Maggie, journalists don't have opinions, but surely your opinion is not that the U.S. Federal Government and Canadian Government should not say one thing in their plans, namely that they're going to vaccinate sick, old people first, then do something else? That can't be what your opinion is, can it?

Maggie Fox:
They haven't really spelled it out. The National Pandemic Plan doesn't say who gets vaccinated first; in fact, it leaves that wide open. Perhaps they want to leave this up to the individual communities. That's one of the shortcomings people see in the plan...is that it doesn't give specifics.

Peter Singer (moderator):
Except that it does recommend as priority group 1B, after you got the health care and first responders, "High risk patients, over 65 with a chronic condition" increases the risk of severe influenza. "Patients aged six months to 64 years with two such conditions, etc." It does say in both the U.S. and Canadian plans: high-risk people next. You're not saying that's not what they're going to do, are you?

Maggie Fox:
I have no idea what they're going to do.

Peter Singer (moderator):
Okay. We've heard that theme before. Which is—and we'll come back to that in the second 20 minutes—there is only so much you can plan in advance because things could look quite different. You're making that point and I think someone else made it earlier.

Peter, what's it going to be? Is it going to be as it is now, in the U.S. and Canadian plans, with the vulnerable people in the next group or should this now be revisited and get the 150 to 180 million healthy 13 to 40 year olds as the second group in the plan? That'll take you quite a few months, right? That's 60 percent at 20 percent a month to get through those folks, and then we'll get to the sick and old people. What do you think? Do we need to revisit the plan or leave it as is?
Peter Gudaitis:
Honestly, I don't think I know enough to answer the question and I don't think anybody does. We just don't know how the pandemic flu is going to affect the population. And until we do, I think it's irresponsible to make that decision. I recognize that we want to have some plans in place. But, what happens if the 1918 flu is the model, and it does really impact those generations? Then it would make sense at the time to shift the plan. But right now, we just don't know. To pretend that we do, creates another idea that we know something that we don’t.

Peter Singer (moderator):
That's a good note of humility. That's the very point that Arlene King, who is responsible in Canada for these plans in part, made in response to this article, namely that the thing may look very different at the time and whatever plan might need to be revisited. Point of fact is that there still are plans that talk about vulnerable people second. Dan, what's it going to be?

Dan Hanfling:
What you’re talking about is the burden of uncertainty. We sort of balance scientific evidence versus the best available scientific knowledge. As reflected by the two previous comments, I think that the public-at-large is going to have to understand that there is that uncertainty. And given the introduction to the dialogue-the same dialogue that we’re having here-to recognize that there are no hard and fast rules. And that whether it’s the 1918 scenario or the 1957 scenario, or some other emerging infectious disease with yet a whole other characteristic of symptom complexes, that we'll have to make decisions as we go along. I think the most important thing to emphasize—from all the stakeholder groups that we’re making those decisions with—is it's in good faith with the best intentions possible.

Peter Singer (moderator):
In a second, we’re going to go see how much of a use it is actually to engage the public in these scenarios, with input in those decisions ahead of time. Carol, where do you end up on this thing?

Carol Jordan:
I just wanted to add one thing to what Dan just said because I agree with what he said. Just one other comment with what we did with the flu lottery two years ago. Most of the people that were "chosen" to get the vaccine were elderly people, although there was a real cross-section of our community in terms of racial and ethnic and so forth. Many, many of the elderly people that came in asked, "Can I give my dosage to my grandchild who has asthma?" We cannot ignore that sentiment from the elderly population. They were speaking very loudly that they were being very selfless in their want to take care of the children and their family. I'm not sure whether that sentiment went beyond their immediate family—an altruism for their whole community—but so many came in that said, "I would like to give my dosage to my grandchild."
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Peter Singer (moderator):
That might be what you were talking about in terms of theory versus practice because that sentiment, for instance, makes a lot of sense. It’s not exactly captured in either the U.S. or the Canadian plan. Sarah, where do you end up on this?

Sarah Landry:
I think I can echo what a lot of people have already said. To the point that Carol just made, I think that one of the "Aha!" moments at the PEPPPI project was when the woman representing AARP got up and said, "Look, my constituents are not going to want the vaccine for themselves, they're going to want the vaccine for their grandkids, and how are you going to handle that, and are you going to be in a position to allow them to give the vaccine to their grandchildren?" That's something you need to be prepared to deal with. I think there are realities and there are experiences from past shortages that we can see how this will play out.

One of the things I would like to reflect on is--now all the flu seasons are a blur so I can't remember which flu season it was--the one that was particularly bad for children in Colorado. When you look back on that experience, there were 160 kids that died for that flu season--those were children, young infants, young toddlers, who were otherwise in good health. When you compare that to the 36,000 primarily senior people in this country who die from the flu every year, you don't get the same level of outrage. I think we do know that when children start dying from pandemic flu, there will be a lot of outrage in this country.

The other points that I wanted to make are: In the discussions in the pandemic flu planning process, I think there is some expectation that some of these decisions will have to be made at a local level, and Peter touched on this when he talked about New York City’s critical workers may be very different than in Texas, where oil is an important commodity that we want to protect. Ideally, I think there has to be a lot of flexibility for local decision-making. I think there is a huge need to go back and have a discussion about this.

My experience from both the PEPPPI project and some research that we have done on communication in focus group testing, is that people’s greatest concern is about fairness and equity, and that was pre-Katrina. Because of that, I think there is even more of a need to be upfront and honest well in advance about what the expectations are going to be. On some levels, this discussion is moot, because we don't have enough [vaccine] right now to vaccinate the health care workers and people at the very top. Unless we get more people getting flu vaccine every year and increase our capacity, there is[n't] much to discuss for the first few months, beyond the first tier.

Peter Singer (moderator):
According to this chart, actually in the first month or so you can deal with that critical level. Then the question is, in April who gets it? Nelson, where do you end up there?
Then I want to get to this burden of uncertainty, advanced decision-making question really to engage whether why, and especially how, one would engage the public in this discussion ahead of time...keeping in mind the various caveats that have come up.

...[NOTE: portion of roundtable not transcribed at participant's request]...

**Sarah Landry:**
We're guessing what the strain that will emerge and cause the pandemic is, because it hasn't emerged yet. So we could start, and we have started making vaccine against potential pandemic flu strains. But it's not clear that H5N1 will be the virus that is responsible for the next pandemic. On some level, it's waiting for that infection to emerge before you can really make a true vaccine against that. We're doing a lot to hedge our bets and do some insurance. The Department of Health and Human Services is planning on stockpiling a lot of different vaccines, against a lot of different strains. But, the virus doesn't exist yet on some levels. You can't make a vaccine-

...[NOTE: portion of roundtable not transcribed at participant's request]...

**Sarah Landry:**
Not the pandemic strain. I think this is an issue that would be worth having a public discussion on. Is it worth investing a lot of money in developing a vaccine and stockpiling it for all Americans for a virus that may never emerge? That's the trade-off as a society that we have to discuss.

**Peter Singer (moderator):**
So what I want to do now is, just capping off this 20 minutes, is to turn to you all to get a sense of how this would look in practice. At the moment, there actually are guidelines—both the U.S. and Canada [guidelines] say, "First responders, health care workers, critical infrastructure, first." The current, existing guidelines do deal with the sick, the vulnerable, the elderly, women and children next—a group of about 30 million people. You're getting into them in April. There's this article that says, "No, deal with the 13 to 40 year olds next." That's a group of 180 million and that would take you at least 2 or 3 months to get through them and then go.

I just want to do a quick show of hands—the existing federal guidelines, both in Canada and the U.S. say "After the first responders, health care workers, etc., go to the sick and vulnerable, that 30 million group next." The proposal out of those bio-ethicists says, "No, go to the other folks next." So let me just ask, who thinks that the existing guidelines—keeping in mind all the issues of flexibility and uncertainty that came up—who thinks the existing guidelines should remain the same, be changed, or [do] you want to abstain? Who thinks the existing guidelines should remain the same, going to those vulnerable groups next, the 30 million people?

Show of hands. Existing guidelines remain the same? Vulnerable people after first responders, etc.? Okay, three people. I think there's going to be an "abstain" group here. Who thinks that the existing guidelines should be changed? Should we go to the 150
million healthy people and leave the vulnerable women and children last? The 150 healthy people next? Who wants to abstain? Okay, so let me just try this again.

[Laughter]

**Sarah Landry:**
There are some other options-

[Laughter]

**Peter Singer (moderator):**
I don't know whether you expected that or not, but that just really freaked me out. So let me just try this again. You see what you just did now though, you're agreeing with the new proposal as opposed to the existing guidelines; is that right? Then I want to get into the value of advanced decision making. This is the PEPPPI fellow.

**Roger Bernier:**
You're provoking a lot of different feelings inside me here. First, I'm not sure you're portraying the recommendations that are out there accurately.

**Peter Singer (moderator):**
They didn't say women and children last. That's true.

**Roger Bernier:**
No, but you've included critical infrastructure in there. I don't think there's as much critical infrastructure included in the current recommendation as you're implying. In fact, I think that what came out of PEPPPI, is that the citizens and stakeholders felt that assuring a functioning society was the highest priority, but again, they were very critical about making sure it was done properly. You have to portray the current recommendation as not as including as much infrastructure as you have.

**Peter Singer (moderator):**
Right. Except that I was lumping U.S. and Canada. And the Canadian ones, I think, actually contain more critical infrastructure on top.

**Roger Bernier:**
Then there's a third option which I think is the one that the PEPPPI group came up and was different from the expert recommendations that would assure the functioning of society in a very tight way, then go to the vulnerable. The other groups didn't compete so well. But anyway, that's just making sure the options are well presented.

But the other thing I just want to say [is] I don't think a lot of people voted. I think what's happening here is that in a way we're not familiar with how, as a group, we can actually work through these things. These people up here were uncomfortable by these choices because they haven't had the opportunity yet to truly engage with one another.
and learn from each other and actually achieve the working through that you can when you do the political thing in the correct way.

This whole alliance is left with these dilemmas and no time to learn and interact and then you say, "Vote." I don't like the approach.

**Peter Singer (moderator):**
That's a good segue to the next twenty minutes, which is how you would have an advanced discussion. As you know, the cynic would say, "You've got a group of folks that spend a lot of time thinking about it (I take all your points). How would you then engage the public ahead of time, given all the difficulties that we've run into [with] this panel?"
The uncertainty, the theory versus practice stuff, the learning that you talked about...I want to turn now to that question of how you would engage the public, given the well-placed comments that you just made.

Maggie, what do you think? Is it [of] value actually to have a discussion in advance about vaccine rationing which is what we've been talking about? How do you do it and what thoughts do you pick up?

**Maggie Fox:**
I can only speak from my experience. I've been writing about the threat of bird flu for a few years, and I've had a hard time getting my organization interested. It's recently become interested, but I find that you have to repeat the message a lot before people become involved or engaged. You have an initial flash of interest and then people lose interest. They can't keep it present in their minds, and there does seem to be something about the human nature that doesn't want to act on anything until it's an imminent crisis. There's probably a good reason for that because otherwise you'd be flapping about, reacting to everything.

I think you have to have kind of a gradual buildup and let people think about things in the background. Then, you wait and see how things shake out. That's not very satisfying in this context, when you want to have some answers. But sometimes you do just have to wait and see how things occur before you really get into it hard and heavy.

I'm already finding now that, again, in the context of writing new stories, we're repeating ourselves. The old news becomes the new news because it's so old everybody forgot about it! Everybody[ has] already forgotten what the original U.S. plan was that accounted for two million people dying in the 1918-like pandemic. When the plan was republished again with more details— that was the lead again, "As many as 40 percent of the people could be out of the workplace..."
I said, "We wrote that back in September. That's old." But it was so old, it was new again. I think it's a long process.

**Peter Singer (moderator):**
So given the difficulties we've seen in this conversation—even about a narrow question
like the existing guidelines in the new article-[in trying] to stay focused, I think the upshot of this morning is, we should engage the public on a question like vaccine allocations. Given these comments and the stuff we were saying before, how should we do that?

Dan? Go ahead.

**Dan Hanfling:**
I would just put [in this]: How we're doing that now needs to be considered in the context of how we would choose to do it with respect to pandemic influenza. We talked about injury prevention. How many people still don't wear seat belts, get thrown from windshields and end up in trauma centers? We talked about stroke identification and chest pain identification as the onset of heart attacks. How many people blow that off for weeks on end before they come in with debilitating illness or injury for the health care system then to pick up the pieces, and hopefully return them to some level of good health? We don't do a good job at that now, with the sorts of issues that we confront day in and day out, so I think it's just important to state that in the context of how we're going to do that with respect to pandemic influenza.

**Peter Singer (moderator):**
Sarah, what do you think?

**Sarah Landry:**
Well, I was going to say some of what we should do differently—we can learn from the national recommendations. I think the recommendations were strong in certain ways, but they were public health focused. They did not reflect across society and across interests. And I think many times what you hear in discussions and what we saw from the PEPPPI experience, is that when you have other people that aren't [acting] as public health experts and looking at this from a medical perspective, their position may be very different, which is why we saw critical workers move up so high.

I remember Carol sharing her experience from the shortage, and there was no way that she was going to vaccinate people without a policeman there to make sure there was order. Those kinds of things have to be taken into account. I think one of the lessons is to make sure that you have broad representation across all sectors of society.

But also I think, to Dan's point—and again, this is based on some of the lessons we learned from communications research—there is an enormous amount of apathy. I think the public is concerned, but they would get angry in focus groups when you talk to them about this and there was nothing that you had to offer them. Frankly, short of washing hands, there isn't a lot that can be done, so I think it's a very hard message and hard discussion to have with people. People want to do something and I think to do this discussion, you have to be prepared to have them having some input—maybe helping to set up guidelines as well.
One of the other things that came through in the PEPPPI discussion was that many people felt that there should be some expectations on the people that got the vaccine. If you’re a healthcare worker and you got vaccinated, you should be expected to show up for work. I think that would carry through with other parts of society. I don’t know if that makes sense, but those are some of the suggestions.

Peter Singer (moderator):
Peter, what if anything would you do, between now and September 2006, when the scenario has the pandemic breaking out, to engage your community in New York on the question of allocation of flu vaccine?

Peter Gudaitis:
I think that the public looks for leadership that they perceive as having moral authority, whether that’s elected officials they trust or religious leaders or community leaders. I don’t know whether or not engaging the "guy on the street" versus a group of recognized leaders that have moral authority in the community are the right panelists, if you will, to have the discussion or not. That depends enormously from community to community. I know in New York City, there’s been an enormous amount of so-called public input into the 9/11 Memorial and as you can all read in the papers on a daily basis, the whole thing falls apart every few weeks. I do think there’s an enormous question mark hanging over my head about how New York can handle that kind of a discussion and whether or not the decision making process would meet at the end of the day with the public's approval.

At the same time, there are communities across this country that are enormously corrupt, where there are serious gaps between public trust and moral leadership in the community that is commonly recognized. So, the federal government does have to take a significant voice in the process and inform that discussion, even at the local community level. I also recognize that people want information that they can understand. So, I don’t think it’s simply an issue of a moral decision-making process about how the decision gets made. People are going to want to understand the facts and the science.

I’m an educated person but I haven't taken a science course since AP Bio in twelfth grade, and I think the average American is not going to understand the science of the pandemic, particularly in the early onset months until somebody can actually as a matter of fact say, "The elderly are not the most at risk; we should be vaccinating the youth." Or, "The youth is not at risk; we should be vaccinating the elderly." I think it’s a matter of science as much as it is a matter of moral interpretation on the matter.

Peter Singer (moderator):
Carol, what, if anything, would you do between now and when a pandemic breaks in Montgomery County to engage citizens of your county on decision-making around vaccine allocation?

Carol Jordan:
We have a very strong senior citizen lobby group in Montgomery County, and they make up a pretty large percentage of the population. So this would be particularly difficult in
counties that have a large elderly and senior citizen population. I know with PEPPPI, we spent three or four long days together, really looking at every aspect of this problem. The group was so diverse—there was a chief from an Indian reservation on the group. There was a woman who was the president of an anti-vaccine activist group. So it wasn’t just healthcare people and the average citizens sitting around. These were people who had special interests and really wanted to make sure that their thoughts were heard.

One of the things that I think is so important—we’re going out, and I’m sure everybody on this panel is doing a lot of public forums, speaking engagements, getting people just to understand our dilemma in making this decision. So that somehow or another, they feel like the fairness and the equity that Sarah talked about [which] is so important, even when we were doing that lottery and people came in with sob stories and brought their sick husbands with them that hadn’t been chosen. They wanted, somehow, to know that we’re sticking to the rules of how we said we were going to do this because there were these priority groups and we worked out this system. So the fairness and equity really leads to a lot of trust in the government who’s going to be running this operation. I think that is so important.

But if people understand that for the first six months or so, vaccines and antivirals are not going to be an option, then they need to feel that they’re not completely helpless. And they need to find out other self-care options, so that they can be as self-sufficient as they possibly can. Not 100 percent safe because no one will be 100 percent safe. But one of the things that we’re developing is a stay-at-home toolkit as part of our advanced practice center in Montgomery County funded by NACCHO. And it’s all the information people need to stay at home and take care of a sick person and not get sick themselves, and whatever they need to do to, at least, know the rudiments of self care and how they can get through the crisis with their own family.

Peter Singer (moderator):
Nelson, Maggie, we’re going to open up in a second. But any thoughts on before a pandemic happens? I’m hearing a lot of caveats, frankly, about public engagement and I’m hearing a lot of the difficulties in it. But what I’m not hearing is how we’ll actually connect those voices you’re hearing.

Carol—back to our guidelines—I’m sure they actually inform your local action which might be the most important thing. Maybe that’s the wrong question as to how they get back to the guidelines, but [I’m] hearing a lot of caveats and not hearing a lot of, "Gee, we should really engage the public and see what they think about this vaccine allocation thing."

Peter, Nelson, Dan and Maggie and then I just want to open up. Let’s be quick and then we can open up.

Peter Gudaitis:
I really appreciate what she just said. I think that the idea of teaching the population how to care for themselves—that sense of empowerment goes a long way [in contrast to]
the sense that the only thing that's going to save me is the vaccine and if you don't get it, we're dead. That snowball effect, even if it's completely false, is emotionally and spiritually catastrophic to the community. Anything that the government can do and anything local non-profits can do to empower the community to feel that they can be more resilient, can recover or prepare to take care of the children and the elderly in the home or whatever.

I think that has got to be a first approach because we know we won't have the vaccine for that initial period of time, and so, giving the community some sense of control over their own destiny in the pandemic. For that matter, what the United States can do for the world, because we do have part of that within the U.S. culture, which is we're here, we're going to take care of ourselves, but we also have this altruistic spirit, which is something that should be applauded. We're also supposed to lead the world in these initiatives, or at least collaborate with other capable partners in doing so. I think that would go a long way to proving that we've done as much work on the front as those of us that have been leaders supposedly in this effort to help the community feel maybe more resilient.

**Peter Singer (moderator):**
Great. Let me get maybe Dan and Maggie and Nelson a couple comments. But while I do that, I want to ask anyone who has some questions or comments they want to make to come to the microphone now, so we have enough time. I'd like to try and focus the discussion on—given what we've just been through—how one would engage the public, say between now and when the pandemic happens, say, on the vaccine allocation issue? But, also, feel free to diverge more broadly if you like. Dan, you've been trying to get in and then we'll take a question.

**Dan Hanfling:**
I just want to add another real caveat, which is that we are now here, insiders talking about the outside world, outside constituencies. We've got a lot of work to do on the inside of the tent as well. In a workforce attitudinal survey that we did in our health system, we found that one-quarter to one-third of our healthcare workforce who are educated, who are dealing with biological disease everyday—they've gone beyond high school AP Bio—they may be deliberately absent for one reason or another or may fall ill. So we've got real workforce issues that come up around these discussion points and to which this level of discussion has to be focused towards them as well. You can't forget that.

Q&A Session

**Peter Singer (moderator):**
Helen?

**Helen Branswell:**
Hi, I'm Helen Branswell, a medical reporter for Canadian Press. I want to pick up on something that Sarah and Carol Jordan mentioned. This is a really fantastic discussion to be been hearing. After three years of covering this topic, I am so delighted to hear
people talking about this publicly. But don't you think you also need to be talking publicly about the fact that [for] most of the world, including most Americans, vaccine will not be available anytime in the first couple of waves of a pandemic? If it's H5N1, that virus is proving to be extremely difficult to produce an effective vaccine for in the kinds of quantities the world would need. Vaccine is not going to be a big player if there is an H5N1 pandemic in the next three or four years. If we're setting up the public to think that's the answer, we are going to have a real, real big problem.

**Peter Singer (moderator):**
Sarah, Carol, you both talked about it, if you will, information and expectations management, that's really what Helen is asking about.

**Sarah Landry:**
No, I think it's a fair point and we do need to manage expectations. Sometimes when I'm asked by people, "What can I do now to prepare for a pandemic in addition to thinking about the things that are often talked about [like] stockpiling water [and] emergency planning for your family?" The other thing [is] that if we want to have sufficient vaccine in this country to protect Americans, we need every American to get a flu vaccine on a seasonal basis.

That's a hard message because that doesn't guarantee that you're going to get protected should that virus emerge, but we need to build that capacity now and we have an opportunity now to start building that. You'll gain something for doing that too; you'll have improved health and be protected from the flu for that season.

I think we do have to be honest with people that there are limited supplies-that frankly, there's not even a guarantee we will have a vaccine. I'm from the vaccine manufacturers, and we are doing our best, and we hope we have a vaccine that will work, but potentially the pandemic strain may not grow. Those are the things we all need to be aware of.

**Peter Singer (moderator):**
Michael?

**Michael Allswede:**
Thank you, Peter. I'm Michael Allswede from the Strategic Medical Intelligence Research Group at the University of Pittsburgh. First, I want to give you ten out of ten Donahue units on your MC efforts here.

[Laughter and applause]

**Peter Singer (moderator):**
Notice Roger's not clapping, but I'm going after him later. Go ahead.

[Laughter]
Michael Allswede:
Secondly, I'd like to commend the panel for wrestling with a very difficult issue. And next, I'm going to disqualify myself as a social scientist. I don't have any ability to comment upon the allocation other than to ask the heretical question that, shouldn't we be talking about geographic allocation in the way that the scenario was constructed?

As you're pondering that thought, I want you to consider for a moment that from the time you get your shot, it takes five to seven days to get an IgM response, ten days to two weeks to get an IgG response, [and] about three weeks to get a cellular-mediated immunity response. And so, vaccination does not mean you're immune at the time you get it. What it means is that in the future, at some point, you're going to develop immunocompetence.

Should we not be using the vaccine where it matters the most, which would mean where the flu is not yet? Then we can prepare those individuals. Specifically, I want to address the issue that six months into an event, a first responder is going to be exposed, arguably in almost every city. Secondly, those who are vulnerable, with the weak and the sick and the ill, may lack the ability to competently respond to the vaccine and develop immunity, so shouldn't there be a medical utility argument that goes into this as well, and isn't geography a part of that argument? Thank you.

Peter Singer (moderator):
Thanks, Michael. I want to pick up particularly on the geography argument. Should we be vaccinating where the thing isn't? Forget about the vulnerable, and the young, and the "this and that." Who's got another theory, as they say in Monty Python? Who wants to handle that? Carol?

Carol Jordan:
I'll start and then maybe Dr. Hanfling will want to add to it. First of all, for a social scientist, you really got a lot of that clinical information right on target. Good job. There are going to be such tight controls on the limited amounts of vaccine, and it's really going to be handled at the national level and then sent out to the counties, so it's going to be very tightly controlled. You've raised issues that we discussed in other venues as well, not today, but I just can't imagine if you have sick and dying people that the vaccine would be sent to someplace where the people are not affected at this point in time, just because of the scarcity of the vaccine. I personally can't imagine that.

Peter Singer (moderator):
Eric, do you have any thoughts on this? On the geographic thing? Then we'll head over there.

Eric Toner:
As usual, I think Mike has a really provocative idea because it's really interesting. I do think, however, from a logistical point of view, it's going to be hard to know where the virus is and where the virus isn't. And I think the virus will be everywhere very quickly, so I think from a practical standpoint, it's not likely to happen. But, an intriguing idea.
Peter Singer (moderator):
So Mike, you've got to write about that, put it in Science, Maggie will cover it and see what happens. Fire away.

Laurie Escher-Pines:
Hello, my name is Laurie Escher-Pines. I'm a doctoral student at Johns Hopkins. We've been talking a lot today about public involvement like it's a checklist item in this process of planning. My question then is, what is our responsibility to actually use public input, and what if the public is wrong? What if the public suggests something that is discriminatory or that doesn't take science into account, and will that affect legitimacy if we involve the public, but then we don't use their recommendations in any way? Thanks.

...[NOTE: portion of roundtable not transcribed at participant's request]...

Peter Singer (moderator):
Carol, you want to take it in, I think?

Carol Jordan:
I just have a quick comment to that. One of the other things I do is HIV care, which I've done for about twenty years. The Ryan White legislation really mandated a system of public engagement that was ongoing, powerful, and continuous. We have to have as part of the planning process, for any of the priority settings or any of the services that we decide on, a group of planners there that includes the ultimate stakeholders, the people that are affected by the disease themselves.

That process can make your hair white sometimes, but at other times, you know that it's not just healthcare providers who have their own point of view for the whole population sitting around a table. It's every voice is heard at that table in terms of setting priorities and how the services should be and the quality of the services and so forth. So, it's way beyond the checklist that you were suggesting. It goes far beyond that.

Peter Singer (moderator):
Got another couple of comments from Sarah and Dan. Just want to point out that we've got about five minutes left, so one more question, little bit of summarization, two more comments, audit and feedback-fire away.

Sarah Landry:
I wanted to add that I've had similar experience to what Carol was saying about HIV populations. I worked in HIV/AIDS National Institute of Allergies and Infectious Diseases early in the epidemic. I will say in the early days, many of the activists were not welcomed into discussions and I think what you saw change was there was an acceptance; that there was a perspective that was important to hear, and if nothing else, many times investigators learned that the studies they had planned were not going to be feasible and "implementable." These were just not going to be accepted. So, I think to your point about what if they're wrong, if they were wrong, or if their scientific
understanding is incorrect, I think it just speaks to the fact that we need to do a better job of working with them to help them understand the issues.

**Peter Singer (moderator):**
Dan, I'm going to go over here and let you be the first responder to whatever this question is and you can always sneak in your answer to the last question in the next one.

**Dan Hanfling:**
Let me answer this question, though, because the public is wrong now. I mean a view of the trenches of emergency departments—where I work overnights on weekends—is that the public is often wrong. We have to expect that they are going to be wrong in the context of making decisions around this very complex issue.

I think the other point back to Mike Allswede's question about geographic distribution, is here we are talking about a U.S.-Canadian approach to pandemic influenza. In this day and age, if we're not considering the geopolitical implications of not only distributing vaccine within North America, but really looking at the hotspots, as D.A. Henderson spent a career doing across the globe, then we're making a big mistake.

**Peter Singer (moderator):**
Thank you.

**Ana-Marie Jones:**
Hi, I'm Ana-Marie Jones, Executive Director of CARD, Collaborating Agencies Responding to Disasters. My issue is that if we fight human nature, we'll lose. Not just sometimes, but absolutely all the time. People will prioritize based on their own personal decisions. On the Titanic, the only group that had a 100 percent survival rate was first class children. Other groups totally prioritized around the income-earner, making sure that the income-earner stays alive and healthy to keep the family moving forward.

I'd just say however we organize this, however the priority list looks like, there's going to be X amount of people for whom that is totally not going to work. The other side of that is to make sure that whoever is at the bottom of the list, and I mean the very bottom, they're at the top of the list for alternative methodologies and strategies. There are tons of things like alternative medical strategies, there's pre-positioning of supplies, there are tools, there are all sorts of things, and we need to break away from this idea that we have this magic bullet called a vaccine. It's not a magic bullet under the best of circumstances and it sets up a false expectation. That is going to be one of your bigger problems, dealing with that and the trust issues.

We also have to acknowledge the fact that we have trained the public that there are certain groups that are the responders and people are basically the victims waiting to happen. Until we acknowledge what is, it's very difficult to engage people in a conversation for what could possibly be.
Our philosophy is that we're not preparing our communities for disasters; we're preparing them to prosper. So looking at this as an opportunity to build those communities into self-helping, self-nurturing, self-generating communities. [That] is absolutely the opportunity that is before us. My question would be: Have any of you considered how to put those alternative strategies in place? Has this conversation even been raised in some of the areas where you're discussing this?

**Carol Jordan:**
Part of our pandemic flu planning has included all of those issues. I think you and I talked about it over drinks last night actually. We're doing a lot of work with special populations and the invisible people; the people that normally don't even come forward for flu shots during the normal flu season, people that have health disparity issues, whether it's racial or ethnic minorities in our county and across the United States.

I think our planning cannot be just the perfunctory things about how to get the vaccine to people. It's very clear that the human aspects—knowing how people react during a fear and crisis situation that it's a normal kind of reaction—all of those things have to be taken into place, so I appreciate your comments. We still have a lot of work to do on that though.

**Peter Singer (moderator):**
Thank you. Élaine, last question to you.

**Élaine Chatigny:**
If I may, it's not so much a question as just something that's been really nagging at me, and one lady before me, I think, made the comment. And I don't know if I'm hearing it explicitly [or] if it's nuanced in anyway or if I'm reading something between the lines that's not there.

I think consultation and engagement is not a proxy, or it doesn't replace decision making in the sense that when we encourage government decision makers to engage with public citizens and consult with them, we constantly have to remind them that ultimately they have been elected to make decisions and to make healthy public policies. But it's an input; it's a source of insight.

It's different than opinion research, which is opinions, which can be more knee-jerk, if you will. But good deliberative dialogue processes or other methodologies that allow you to have a conversation with people about the trade-offs, the difficult choices that as a society we all have to make. We make tradeoffs in our daily lives anyway. We're accustomed to that. We're hard-wired to do it. It's an important input to the overall process that the government decision makers have to engage in. For example, what we're proposing in Canada is consultation as one component of overall decision-making.

I think that I hear sometimes that if you engage citizens at all, whatever they tell you, you have to act on it. No. There is a risk associated with ignoring the values and the beliefs that people here hold deeply. But, you have to manage that if you make a
decision. You have to be able to explain why that's not being acted upon. But that's life, isn't it? I felt that it was important for me, anyway, to articulate that our view in Canada in encouraging consultation is not to usurp the responsibilities that government leaders and decision makers have.

Peter Singer (moderator):
Thanks, Elaine. That's a point well taken. Before I summarize in thirty seconds, Maggie, I just wanted to ask you what's the headline in engaging the public in vaccine allocation before a pandemic hits?

Maggie Fox:
It's not going to be engaging the public. I think part of the problem here is that very phrase "engaging the public" is really vague, and it's academic speak, and you have to come up with something more like, "What's your vote on this? What's your opinion, what's your vote?" I was sitting here thinking that if you want to encourage people to get the flu vaccine every year, what they're doing is voting for public health capacity. They're voting for the companies—it's like shopping at your favorite store. If you want your favorite store to be there, you've got to shop there, so that they stay in business. "Keep it in business." It's going to have to be something along those lines, something snappy that people can understand—"I'm doing this, expressing my opinion in order to take part."

Peter Singer (moderator):
Great, thank you. Let me summarize for thirty seconds before I thank the panelists on your behalf.

What I got out of this was number one: From the morning sessions, it's clear that people think public voting, whatever the right word is, is a good thing. Number two: When you actually sit down and try to do it on a specific scenario, it isn't that easy. Part of the reason it isn't that easy is the point that Roger made when he wasn't clapping, which is, you could do this with 300 people for a couple days, and that gives you a really in-depth and good discussion with feedback. I think your PEPPPI thing is a really, really great example of that. The question is how you might upscale that from 300 to 300 million using mass media, not to 300 million, but a much, much larger group of people.

What became really clear to me was [that] the main uses of public discussion before an event around an issue like this is actually getting some good information out and some reasonable expectations out. It's actually the stuff you can't do—can't have a vaccine against the strain for six months; even in six months, it might not work. All that expectation management, if you will, it might actually be one of the main reasons to do [citizen engagement] as opposed to the feedback to change your guidelines which was what I was hammering away at earlier on.

Your point Peter—and Carol, you made this point as well-around the importance of engaging local community. And even if you don't get the feedback and change your guidelines based on Zeke's article and Maggie's thing about it. Carol, your discussions with your local community will likely guide what you do later on. So, it's this more
nuanced, more subtle, difficult-to-measure stuff at the interstices that actually may be the main point. Having said that, all those caveats leave me with the idea: we better get out there and start trying some models. PEPPPI is a great example of that.

Because the way to answer this question of how to engage the public, of course, is not a sort of theoretical simulation but actually getting out there and doing it, seeing if it works, trying something else given that it doesn’t, and learning a lesson as we go along. So with that, I know that wasn’t a perfect summary, just some reflections on what came up, I want to thank our panelists. I want to especially thank Roger and Eric. Roger for your intervention, and Mike. I want to thank our panelists on your behalf. I want to thank all of you for being involved and thank you very much. Now we can move on to the next one.

[Applause]

**Monica Schoch-Spana:**
To Peter for a wonderful job as a moderator and to our panelists again. We're going to take a break for ten minutes and start sharply at 3:15 to consider our second Roundtable Discussion. The concern was raised in this panel if we don't have vaccine, then what do we have? Some of those issues will be addressed in the second panel regarding mass casualty care. So please return promptly by 3:15. Thank you.

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**Roundtable II**

**What Happens If Hospitals Cannot Take Everyone In?**

**The Problem of Meeting Immense Medical Needs**

**Monica Schoch-Spana:**

It's my pleasure again to introduce my colleague, Dr. Tara O'Toole, the director of Center for Biosecurity who's in chair number four from the left. Everyone is seated from left to right according to the names up there [on the slide], and I'll let Tara take over with introductions and open up the scenario.

**Tara O'Toole (moderator):**
Thank you, Monica. Can everybody hear me? We're going to change the format around a little bit this time. I know it's late in the day and everybody's exhausted from trying to save two nations from a terrible pandemic, but we're going to see if we can rev you up again.
Rather than try and compete with Donahue, I'm going to try and take myself out of this conversation except as an occasional provocateur and try and get the panel here to talk to each other as those negotiating actions during a flu pandemic. But before we get to the scenario, let me introduce people and explain who they are in real life and who they're going to be for the next 50 minutes.

On the far left is one of our token males. We have Dr. Richard Waldhorn. Richard is a distinguished scholar at the Center for Biosecurity. He was, in his previous incarnation, a critical care physician at Georgetown University and chair of the Department of Medicine there. He is focused on hospital response to pandemics and bio-terrorist attacks since his time with the Center.

Next to Richard is Commander Robert Tosatto. He is director of the Medical Reserve Corps in the Office of the U.S. Surgeon General. He's been in the Public Health Service since 1988 and served as a responder to a number of disasters including the 2001 anthrax mailings and the refugee crisis in Kosovo.

Next to Rob we have Jan Lane. She is currently the deputy director of the Homeland Security Policy Institute at George Washington University. From 1990 through 2005, however, Jan worked for the American Red Cross in a number of positions, most recently as the vice-president of public policy and strategic partnerships.

To my left is Diane Lapson. She is president of the Independence Plaza North Tenants Association. This is a housing complex in New York City with 3500 people about three and half blocks from the World Trade Towers, and they were in the middle of the red zone during the attack on the World Trade Center on 9/11. She is a founder of the 9/11 Environmental Action Group, and in her free time, she works with music publications in the entertainment industry.

To my right is Dr. Christa-Marie Singleton. She is the chief medical officer in the Baltimore city Office of Public Health Preparedness and Response. She has been a pediatric emergency room doc and she's worked in a variety of policy positions in Washington D.C. as well as a county health officer.

To her right we have Arrietta Chakos. She is the assistant city manager in Berkeley, California. And she has been a very active citizen in preparation for seismic safety. This work has involved her with policy makers, with FEMA and with U.S. and Japanese collaborations.

And finally, not least, we have Ann Beauchesne. She is the executive director of U.S. Chamber of Commerce's homeland security division. She previously held a number of positions in the National Governor's Association including director of Homeland Security and emergency management for the NGA.

Tara O'Toole (moderator):
So, clearly we have a diverse and distinguished panel. We are in the middle of a flu
pandemic. We are in our community, which is a city in the District of Columbia about to reach the peak of the pandemic though we don't know that yet. There are two times as many patients for every ventilator we have. We've got about four or five patients for every available hospital bed. People are very sick. We haven't been able to figure out the mortality rate yet, but it's much higher than the 1-2% mortality rate of 1918 and looks a lot more like the 50% mortality rate that we're seeing now with H5N1.

I'm going to ask people to play very generic roles which stem from their real life experience. Rich is going to be Mr. Hospital. He is going to be both a medical director and CEO of a major hospital in our city. Rob is basically going to be the entire federal government-a dream come true, yes, the stuff of which nightmares are made. But in particular, he is going to be the city's link to the feds and to HHS and we're going to ask him a lot of questions about the Medical Reserve Corps and what the federal government can do for us.

Jan is going to wear two hats. She's going to be a talking head representing a think tank for the media and we're also going to ask her, at times, to be Jan Two and serve as our representative to the American Red Cross and other citizen volunteer organizations. Diane actually gets to be herself. She's going to be Ms. Citizen Activist representing her neighborhood. And then we're to have Christa be herself; she is going to be our public health representative for the city and we may ask you to be the state as well. Arietta is going to get a promotion and be mayor or city manager. She's going to represent our elected officials. Ann is going be the entire private sector.

OK. So, here we are. Things are looking very serious and we are going to try and figure out what to do about delivering medical care in some coherent way that provides people with dignity and a sense that the entire community and its values are not coming apart. So Richard, what is going on? What do you have to say about this situation?

Richard Waldhorn:
Well, let me tell you about our hospital. It's not going too well. Despite years of plans and drills and exercises, the real thing is a lot worse than we anticipated it was going to be. All of our flat spaces in our hospital have been converted to patient care areas. We've gotten out of mothballs any beds or any equipment we had in our stockpile. We've used every mechanical ventilator that we have, but more difficult than that, we have a large amount of absenteeism. Even when we have a ventilator free from time to time, it's tough to get a respiratory therapist or nurse available to staff that case, even though we've spread patients out to other wards of the hospital.

Our elective procedures have been canceled in our hospital and my CFO is telling me there's not too much more cash flow left for my hospital because I make my revenue on those elective cases and those are drying up. So I'm running out of cash to run the place.

I have no more capacity in my emergency department. They would be on re-route but there's nowhere to re-route the patients to, because the other hospitals in the city are reporting the same phenomena. We are unable to care for patients with non-flu
disorders such as our diabetics and our patients with heart failure and our children with asthma. We're short staffed in all clinics and our routine care is suffering in our community. We don't really have any more capacity than we can generate within the four walls of our institution. We've done about as good a job as we think we can.

We're now in two places in the hospital beginning to face decisions about limiting the amount of care that we can give. In our emergency department we're going to be forced to make some decisions about who we can admit, whether [we have] the ability to impact those patients, or whether they are too far gone for us to admit. And similarly, in our intensive care unit we have patients with very high mortality, multi-system disease and [for] whom it's not clear whether the extension of resources is going to do them or anyone else any good.

**Tara O'Toole (moderator):**
Wait a minute. So you're telling me you're going to turn patients away from the hospital? You're going to tell them they can't come in when they're very ill?

**Richard Waldhorn:**
We need some help from the community in this regard. We need a framework in which to begin to make these decisions. We're at the point now where I'd like to get some help from the public health department, from community groups. Because we're at a point now where we can't develop any more capacity. We have to start limiting the amount of care that we can provide so as to do the greatest amount of good for the greatest amount of people. And we're going to need some kind of input from our community engagement or our community in making these tough decisions.

**Tara O'Toole (moderator):**
OK. So you call the Mayor and public health department and they've called this meeting.

**Richard Waldhorn:**
And one of the things....First of all, I want to know, is there any capacity anywhere else in the system? Are there any resources that be shared anywhere in the system? We've drilled and practiced that as well. My hunch is, from hearing my colleagues around the city talk, they're all in the same boat. But I would want some intelligence, some situational awareness about the rest of the city hopefully from my colleagues in public health and in the private sector and in the rest of the community. First of all, is there any capacity anywhere, and if not, how do we go about beginning to decide what care we're going defer to do the greatest good for the greatest number?

**Christa-Marie Singleton:**
Well, from a public policy perspective, I guess one of the first things we would ask is-well, I'll tell you what public health is going to definitely be doing, [it] is actually being a little bit behind the eight ball in terms of trying to investigate the cases. Unfortunately, public health's capacity to do that is basically very limited in that we usually only have one or two fully trained epidemiologists on staff. We're very, very good at doing case controls and trying to catch up with people. But it's the case of taking one or two
individuals that have their normal full-time job and then trying pull them up to do more and more investigations. So, we would be stressed at this point.

If we're maybe halfway through an eight week epidemic, about four weeks into it, you've used up the majority of our staff. We probably too would be having some staff absenteeism. And so, a health commissioner at the local level will likely be reaching out to the state health commissioner to say, "Please help. Do you have any available staff? Do you have other disease investigators? Who else can you think through?" Hopefully this health commissioner will have done some cross-training on their staff. So looking at nurses, social workers, and others who can ask basic questions and try to find these people who are either A) sick or B) potentially sick--and try to get them to either stay home or do preventative measures.

The challenge for our colleagues at the hospitals is to say, "OK, who's going to be message maker? What are we going to tell the public?" 'Cause if you're saying, "I'm full, I can't take anymore people," where can sick people go? Then one of us has got to be the messenger to the public.

**Richard Waldhorn:**
Feel free.

**Christa-Marie Singleton:**
Give a consistent message to the public. And then it would be a local level almost competing with, in some respects, the state to say who's going to be the main message maker. And hopefully in this state of... whatever we are... here would be a good dialogue between public information officers at the local level and the state level. So there wouldn't be a local person saying, "We're in trouble" and the state person saying, "We've got it together" or vice-versa. I could see a tension, and turn to my mayor, with the emergency medical system because you'd usually be a on re-route, but the EMS people will still be getting this influx of 9/11 calls and they're going to be picking up people and dumping them at your door anyway.

In a lot of communities, the EMS community is using these Homeland Security funds to say, "Oh, surge capacity. Let's buy all these tents." So they may come beating my door as the health officer, or you as the mayor to say, "Let's put up these new tents we have and let them help the hospital out. We can put them at the door to give you some extra space." The challenge for public health is if we do that, then how do we track these people, and how do we provide appropriate care for them?

**Arietta Chakos:**
Well, let's see. A very appropriate response from both of these members of our community...

As the mayor of the city, what I would do is really use the California model, the incident command system, to make sure that we're talking with all the right people in our community. I would invite our colleagues from the private sector, from the American
Red Cross and the volunteer community immediately for a meeting to start looking at where we can house people for palliative care and get some volunteers in from the community so we can start to provide medical support where our hospitals and local clinics are overwhelmed.

The second step I would take would be to get in touch with our colleagues at the federal, upper [tier] at the state level too. Because we have a very ordered system in California on how to handle these sorts of things and route all of our resource allocation requests through operational areas, our counties, up to the state. I imagine that we would be asking for state and federal assistance and activating Medical Reserves Corps.

Tara O'Toole (moderator):
OK, this is not California. This is D.C.

Arietta Chakos:
OK.

Tara O'Toole (moderator):
There's none of this....

Arietta Chakos:
There's no...?

Tara O'Toole (moderator):
Everyone is overwhelmed.

Arietta Chakos:
OK. So we're not to get any outside support?

Tara O'Toole (moderator):
You're not going to get any outside support from the state. In fact, you can't get the state to return your phone calls because they're getting phone calls from everybody. And let me ask our Red Cross representative: Are you ready to send volunteers in to take care of sick patients for a disease with a 3% mortality rate or 2% mortality rate?

Jan Lane:
I think you have to. Hopefully, we will have had this conversation before—Red Cross would have been a part of the planning. There'd be the understanding about where we can and where we can't send volunteers and where we'd need to keep them safe and what the limits are to what they can provide to the mayor and to the public health department. One of the areas where we can be of tremendous help is to take a look at who are the trusted messengers to get some of the key messages out to the public. Why is the 9/11 system overwhelmed? Because you're probably getting a lot of calls from the worried well. How do you reach those people with the information that they need to empower them to know what to do? You go through trusted messengers.
So let me take off my Red Cross hat and let me go to the faith-based community, because we’ve seen time and again that the faith-based community does have that forum to get the messaging out. They are the ones that are going to reach out to the vulnerable populations. They have incredible networks of networks to get that message out. But from the standpoint of these partners, hopefully they and the Red Cross will have been at the table, and part of the discussions will be how the community can rely on us in the way of volunteer management. What is it we can do for the local hospital? It's not going to be administering vaccines, but it may be helping the information flow-some of the phone bank calls that you may be getting from the worried well.

Because, I think, any time we are able to empower people to know what to do where is the sheltering place, how to prepare in advance-we'll take that burden off of the 911 system, again, overloading EMS. That is definitely a concern as we go through this.

**Tara O'Toole (moderator):**
Diane, do you think it would be helpful to have hotlines that citizens could use to get basic information and non-emergency....

**Diane Lapson:**
Am I on? I hate to say I told you so, but if the public had been educated all along on what to do in an emergency, we wouldn't have to wait to be trained and we could immediately move into action. So I've seen, since I live in Washington now with a Brooklyn accent, I've seen that in neighborhoods-say in downtown Manhattan during 9/11-that there are hundreds of people that came forward to help. That wasn't a disease, so in those cases, whatever they were doing worked because it had to do with food and we weren't contagious.

But I think in this situation, one of the important things to remember about the general public is that everyone's traumatized. So, helping is part of healing their trauma. And if they can get involved you'll have that many less problems on your hands. I think everyone, no matter who they are, can do something. I think that we probably will need to get public spaces like one of the hotels that exist in Washington, and a conference room this size, and try to see how we could get people who were sick over there. And then have the instructions on what we could do without getting sick ourselves.

Something that's really important is that none of us have any supplies. And if we're working with the sick and breathing everything in without a mask, we'll be the next ones to lie down. But, I think that history has proven that people are not going to leave. They're going to stay. They're going to be the ones driving the sick people back and forth to where they have to be. So, I personally think the radio system is the best way to go and to immediately go into a mode of: "Here are the instructions, and here's where we need everyone who's a nurse. Everyone who's a social worker show up at this location. Everyone who's an electrician come here." And just start telling people where to go and give them immediate instructions. Problem is, you have the people to train the volunteers.
Christa-Marie Singleton:  
Actually, one of the bigger problems is: What is the message? Because, it's got to be very, very simple. Public health has had a history of being very positive about just simple messages. The challenge though is that we as the community, as the public, have not always gravitated to those. If there's no vaccine, there's no antidote—at this point we're talking probably basic respiratory hygiene and just really reinventing that and underscoring that more and more and more.

And either having a public health person or a hospital person, however we decide whoever is going to be [appointed]. Say that I'm [appointed]...then, a compassionate way of saying it: "This is what we want you, the public, to do, and we need your help. If you volunteer to help, we will do our best to protect you."

Public health has to spell out how people can protect themselves so they can help other people—covering their mouths or... maybe you can help out being on the phone bank. You can help out by delivering food. You can help out by watching someone's children so they can go to work. Whatever. But we, as public health, have to step up and tell people how they [can] protect themselves. Otherwise, we can't expect them to help each other.

[crosstalk]

Ann Beauchesne:  
I would just add that if we're going to wait to have the conversation with the private sector, wait until a pandemic happens, [and] then say, "Gee, let's figure out if we use this hotel. Gee, let's figure out if the trucks are still going to go," we're going to have absolute chaos. What needs to happen now is with the money going out to the state for pandemic planning—the money that's going out from DHS—as a part of getting that money, every state should be required to show how they're incorporating the private sector into their plans, their training, and their exercises. Unless that happens you're going to have chaos. You can't wait until this rolls out to figure out how you're going to include the private sector.

We also need to figure out, ahead of time, what capabilities and assets the private sector has in your area and can bring to bear. We have the EMAC, the Emergency Management Assistance Compact. We should have a similar version of that for the private sector to figure out who has what, who can bring it there, especially at a time when you're going to have a minimum of a 40% workforce issue. That's going to be essential to figure out what the exact capabilities are.

Tara O'Toole (moderator):  
I think all the guidance that's come out from the state and federal governments has been to include this kind of community planning well in advance of disasters. Karen Marsh spoke earlier today about the Citizen Corps mission, and how we have to start talking right now. So, I think that when our health officer Christa starts talking about the consistent message, she has to be flanked by people from the faith community, trusted
community leaders, as well as the private sector and your elected officials, of course. And we're looking at as well how we can begin to give people, as Diane was saying, some tools to work with in the short term. [And getting] messages out through the mass media of consistent hygiene and self-care message as well as caring for others within your community will all be essential in the short term.

Richard Waldhorn:
You know, Tara, two things were mentioned here that came up on rounds in the hospital. One was about, what about setting up tents in the parking lot? What about using some of the hotels downtown for patients? But my staff was very worried about these two ideas because they're already having enough trouble segregating out those who are infected with flu from those who are not as they [become] present to our hospital. We've run out of rapid flu tests; we're not sure if it works anyway.

We are worried that our hospital is becoming an amplifier of the disease. We've had cases of our own staff becoming ill. The patients who are coming in the hospital are very, very sick and we're not sure what we'd be able to do for them in a setting where we didn't have oxygen, suction, mechanical ventilation, etc. So I'm not sure what we'd do if these tents or hotel ballrooms become full of patients other than perhaps amplify the disease even more in the community. I wonder if the public health office has an opinion.

Christa-Marie Singleton:
I would definitely agree. In fact, in my real world life I'd advocated against the active purchase of these, because again who's going to staff them? Even they become just sick bays, we don't have any staff. So, until we have better technology and staffing, I'm kind of moving away from that. My goal is, in both my real world life and in this life in this scenario, is trying to get that message out to say, "Really, public, don't go to the hospital." It's almost what we did last year with the flu...two years ago with the flu vaccine crisis. "Don't go to the hospital. If you're sick with A, B, or C, go home or stay home."

One of the challenges though in this scenario-what I would do is look to my mayor and say, "We're really going to advocate that people stay home. But if they do so, particularly if they work in the private sector, they're going to lose revenue. Do we have any kind of financial revenue that we can use to support them staying home?"

Tara O'Toole (moderator):
Before we go to the revenue [question] and the private sector, I want to stay on, "What do we do about managing all these sick people," for a moment. This seems like a situation tailor-made for the Medical Reserves Corps. Commander, can they help us here?

Robert Tosatto:
Potentially. In working very closely with the public health department. The Medical Reserve Corps are a resource of medical and public health providers to supplement the existing local resources. So, to that extent, the local public health department would use
their staff, their resources to meet the needs. Then those are tapped out, and then they could call on these extra resources from the Medical Reserve Corps. To that extent, they may be helping at the hospital—maybe, maybe not.

But they could also be helping with the goals of getting the word out, getting the messages out. Maybe manning some of those hotlines to answer those questions, where the staff can then do the disease surveillance—do the other things that are needed everyday. The volunteers can come in and help out with this. If there are other sites open—alternative care facilities—then maybe some of these volunteers could help out in those types of situations. We've seen a great outpouring of volunteer support to natural disasters—after hurricanes, after situations like that.

**Tara O'Toole (moderator):**
Isn't this a little different? We've got a lethal disease that you might catch by being altruistic.

**Robert Tosatto:**
This is quite different. This is quite different, and I don't think any of us have a great deal of experience. We're not planning...in our planning, we don't have great confidence in large numbers of individuals coming to help out. But, we know there will be some that will show up. We've seen in every type of situation [that] people are willing to help. What those numbers are, we can't guess that. So, for planning purposes, our goals are to have a lot of MRC units so that there are more MRC units to draw from. And within those MRC units, to have lots of people sign up, and hopefully you have a bigger pool to draw from within that.

**Diane Lapson:**
It's, of course, a very difficult decision to make. I don't know which is better—having a lot of people sick in their homes [alone or putting them in a central place]. It could be a mother with her children and suddenly the mother falls ill and the children are there by themselves. And if we don't have them in a big facility, then how do we know which apartment or which house has people who need help? So, on one hand, getting people to a big facility is a risk, but on the other hand, having everyone in their individual spots is very dangerous too, because we don't know how far the illness is even going.

I think, if we had to do it that way [asking people to stay at home], then it would be easy for the public to get involved because they could become captains—just checking in each house or building or block to see what's happening in each house. But I don't know if that would be good way—maybe, unless maybe Red Cross could go and visit each one of those houses, how would we treat people that way? So, it's definitely...I don't know if one way is better than the other. It becomes so tremendous, where you're taking children out of the house because there's no adult left that can function.

We have to have facilities anyway, even if people are well—shelters to put people into. I know during 9/11 they turned all the—about five high schools into shelters, when people lost their electricity and they had to go there. But at least we knew 300 people are in this
spot; 50 people are here. So it becomes dangerous if...and I also think one of the problems, the negative aspects of what happens in a disaster, is that people left alone and not part of a community sometimes mentally get unbalanced. And I think the community aspect in whatever way—it’s playing a role [as] the healing spot. And it’s the group of people coming together. So I think, just thinking about everyone staying and sheltering in place can’t be the final—I don’t know if that’s the final....

**Tara O'Toole (moderator):**
What do you think about that, Mayor? You’ve got your public health person telling you the best thing to do scientifically is to keep people isolated so they can’t transmit the disease. You’ve got your citizen activist telling you she thinks that it’s going to deal a real spiritual blow to the community and it’s not going to go over well.

**Arietta Chakos:**
I think that’s a very strong point that we have to look at. As Ms. Chatigny said earlier, decision makers have to make decisions. And so, I will be making sure that I consult with the medical community, but basically we have to have some kind of hybrid model. I think that looking at the Community Emergency Response Teams that so many communities have established and using the networks that exist, whether it’s through Neighborhood Watch or just neighborhood associations, that we can become a little more nimble in how we respond to this.

I think leaving people in isolation is a mistake. When we look to the 1918 Spanish influenza pandemic, we saw that people actually behaved in a very altruistic and community-minded way. I have no reason whatsoever to think, at this point, that will be different in a pandemic situation now. I think also that we have to look at the assets that communities have. Ana-Marie Jones talked earlier about the whole notion of a community that builds on a positive and healthy approach to connecting with one another. And this is something I don’t think we’re looking at right now.

There is an article published in the April, I'm sorry, September '05 issue of Harpers magazine by Rebecca Solnit. It's called "The Uses of Disaster." And she is a UC Berkeley journalism professor who took a look at how communities and government responded after Katrina and September 11. And really, our biggest assets in all of this are the community members and residents in our cities. And we have to use them as a strength and not look at them as this sort of detriment to healing and responding to disaster.

**Tara O'Toole (moderator):**
Certainly, the private sector was important in a lot of the response to Katrina and by some lights was more effective and efficient than the federal government end. You’re the CEO of a large corporation downtown. You’ve got thousands of employees. You’ve got many buildings around downtown. You’ve got a lot impressive communication infrastructure. What can you do for Richard?

**Ann Beauchesne:**
First of all, again, I would hope you’d know each other prior to this. Second of all, I’d be
wondering where I'm getting my information, how good that information is, and making sure I'm communicating first to my employees, second to my vendors, and third, figuring out what left-over assets we have to build to help the community. I would say that hopefully we'd already be built into the community plan, so they would [know] what we have around town, what transportation we have, what housing we could provide, that kind of thing. Certainly the private sector, as you said, was ready, willing, and able to help out after Katrina. I think the logistics and management capabilities far exceeded the federal government and state government, and they should be tapped on and looked at as a model during a pandemic [and more].

**Tara O'Toole (moderator):**
Can you think of anything specifically that the private sector could do for hospital response, for taking care of all of these people? Hospital response is probably too specific—medical response, taking care of floods of sick people in a pandemic?

**Ann Beauchesne:**
Do you mean for staging?

**Tara O'Toole (moderator):**
Whatever.

**Ann Beauchesne:**
Yeah. For that, certainly, these larger stores could provide a place to put beds. The transportation issue is going to be huge. You're going to find people, are we going to have enough people to drive the trucks? Are we going to have enough trucks? Are we going to run out of essential supplies very quickly. We're not stockpiling anything. Certainly, we're not stockpiling ventilators, we're stockpiling even the needles to give the vaccine if we were to have one that doesn't exist. A lot of those things, though, need to be looked at and pre-positioned and talked about ahead of time, or, again, we're going to find ourselves behind the 8-ball.

**Tara O'Toole (moderator):**
Jan, you're now a talking head representing the George Washington (GW) Homeland Security Institute on television. They've just gotten a report that Richard's hospital is turning away ambulances from the door, saying they're full up. They can't take anymore sick people. There are reports that someone has actually died outside the hospital because they couldn't get in. The commentator, I guess that's me, asks you for your reaction to this. What would you say at that point?

**Jan Lane:**
First and foremost, the way that we operate with GW's Homeland Security Policy Institute is that we're functioning as a bridge, we hope, between the policymakers and the practitioners, so these would most likely be people that we may have had conversations with before. We may know their concerns; we may have been part of conferences like this. In an era where misinformation—we've seen the damage that misinformation can cause during a disaster—I'm going to try very hard to get my facts
straight very quickly, knowing that everybody else is on deadline and trying to meet their needs.

I'm going to check with the hospital, I'm going to try and run things down. I'm also going to be checking, what are the messages? What are the key messages that have to come out from a public policymaker standpoint and their local public health department? What is the most logical, most practical, most calming statement that could be made that's factually correct, that moves the ball forward, that doesn't disintegrate into a finger-pointing exercise?

[eight seconds of silence-previous section repeats]

**Tara O'Toole (moderator):**
What you just said triggered something. If a hospital turns somebody away, and the person dies on the steps, in that case wouldn't it be better to have a secondary...no matter how dangerous it might be, a secondary location at least to take those people who cannot fit in the hospital, and put them somewhere and have some kind of assistance? I mean, public relations-wise, you're certainly not turning them away just because you don't care, but just to say to somebody who has this horrible disease, "We can't take you; you're on your own," is already making it look like what you're doing is wrong when actually we could do something.

**Jan Lane:**
But I think that's also getting back to running down the facts. Were they in the midst of transporting that person to a VA healthcare facility that may have that excess bed capacity, and this individual was so ill at the time that's just what happened? I mean, that's where we need to really nail down the facts. What did go on in the Superdome? What exactly was going on in New York? All of that, it's so hard to sort through and get the facts when there's such chaos in initial reports.

**Tara O'Toole (moderator):**
But I think there's two generic points here that are worth highlighting. One is that in an epidemic, there is going to be a very thick fog of uncertainty and rumor-mongering. Anything that we can do to slow down people's leap to conclusions is probably going to be constructive and useful. We're also going to have to have a rich network of communications among all the decision-makers at different levels, which far exceeds anything that we have now or have ever put together in modern experience.

The other point, I think, is the one that Diane made, which is that the dignity of how we die is as important as how many we save. We need to think about how we're going to deal with the demands for care that are going to exceed our ability to deliver anything close to what we now regard as acceptable standards of care. It's late in the afternoon and I want to take some questions from the audience. I don't think we've solved many problems yet, though I think we hinted at some solutions or at some of the priority problems, but what I would like to do is...
Robert Tosatto:
I want to bring up one point.

Tara O'Toole (moderator):
You are the federal government. You get to butt in and say whatever.

Robert Tosatto:
Nobody asked for the federal support, I noticed. I think that is a good point to take home from this, and I think that's one of the points of the meeting today is the community action, the citizen involvement, the local activity—that these issues are being handled at the local level. The Feds aren't going to be able to come in. You saw the quote from Mike Leavitt; we're not going to be able to ride in on the cavalry. We're going to be hopefully in advance providing some good guidance, hopefully in advance being able to provide some of the support, whether it's technical assistance, whether it's financial. But when the event happens, I think this is the appropriate thing that would be happening is that meeting being called at the local level.

Tara O'Toole (moderator):
Well said. I'm going to go around the panel here and ask them if they have one wish that they could achieve by waving their magic wand today, four months before the pandemic strikes, what would it be to improve our ability to manage people who are ill and, in particular, improve public participation and cooperation and collaboration in managing the floods of patients? If you have a question, please come to the microphone while we're going across the panel and we'll get to you at the end. Richard, would you like to wave your magic wand?

Richard Waldhorn:
If I could wave a magic wand, there would have been already a serious discussion in the country and in every community about the situation of the demand for care exceeding the ability to deliver it and the ability to make decisions about limiting care. I think at some point our capacity will be reached, and we'll have to start figuring out how to deny care in a graceful and dignified and egalitarian and transparent way. Maybe what's as important as what we can do, is figuring out what we cannot do and how best to make those decisions.

Tara O'Toole (moderator):
Rob?

Robert Tosatto:
I would say a sense of personal preparedness and a return to self-reliance, family reliance, that ability to care and understand what the needs are for the individual, the family, the community, rather than reliance on others to help.

Jan Lane:
I think, at this point, my magic wand would be—managing expectations would be first and foremost. But then it would be moving from plans to implementation and doing so
by training and exercising, and making sure that we have absolutely everybody that's needed at the table, because this is going to take non-traditional first responders. D.A. said it earlier today, and it was [that] we've fallen into that legalistic definition of first responders instead of trying to understand that the first-response community will morph and change depending upon the disaster. If we have an empty seat at the planning table, we're going to have a kink in even the best-laid plans.

**Tara O'Toole (moderator):**

Diane?

**Diane Lapson:**
Are there community boards in every state? Do they have what's called community boards? OK, I guess not. In New York City, which I've heard they have, in New York City, they have community boards for each community, and those community boards make resolutions and talk to the Mayor's office and the City Council, and much of what goes on in those communities happens at the community boards.

So if there are no community boards... I would say that the Department of Health, my wish would be, that now, this moment, the Department of Health make an announcement that it's going to meet with all CERT members, citizen's emergency response teams, and community leaders and other interested volunteers, to have a public health meeting, and right now decide who you can call in an emergency and what those people, who they'd be responsible for, and begin subtly educating through those groups and through television, start educating people so that at the moment of disaster there is no panic because you know you're going to get the constant communication.

I think now is the time to identify who is going to respond in the emergency.

**Christa-Marie Singleton:**
My wish is very similar to yours. If I had a wish, I would like to have a workforce, and that workforce is not a paid workforce per se, but a workforce that is built of business community people as well as the members of the neighborhood associations, because I do stand firm with the idea that it's probably better that people stay at home. We've talked about the training. We've talked about other natural disasters, but it's not an illness, and when it's an illness people tend to want to also stay at home. They like to be close to their surroundings, close to their family.

I look at the Toronto SARS experience—my public health colleagues up there who used that time to make those phone calls so that people weren't so isolated, to check up on people. We're going to need a workforce that is built of public health people, business community people, community activists, that will be ready to stand up and help us by making those phone calls and protecting themselves and helping out each other, so that people can either be treated with dignity in sickness or in health.

**Arrietta Chakos:**
I'm going to go for two wishes. My first wish is that we will continue to strengthen our
communities so that they can be resilient in a natural disaster and a medical disaster. My second is to have a more robust and authentic partnership with the Federal government for local-level municipalities. If I go to another meeting and, forgive me, Mister Federal Government, hear the federal government tell us that we're on our own, I think that I'd probably run from the room and scream. I would like to move it from a "level one, one-way arrow out" to the locals to that "level five of interaction and partnership" that Ms. McKinnon showed us this morning, because I think only then, with the local, federal, and community people working together, will we have a decent chance to make it through such a situation.

**Ann Beauchesne:**
I think-I would hope-that the governors of the states would call the CEOs in their states and say, "Here's our pandemic plan. Let's talk about expectations-yours and ours. We're expecting that we'll be able to use a couple of your facilities for mass care or, God forbid, for bodies when they start piling up, or we're going to hope that the truckers keep coming through." Let the private sector ask, "Are you going to shut down your borders? What do we do then? How are we going to keep food coming in?" To have those very frank conversations about expectations on the private side and the state side, and as well as down into the local level. I think it's all well and good to have plans, but we're not talking about, "This is what we think this plan really means and this is how it's going to be executed."

**Tara O'Toole (moderator):**
Those were all very modest magic wands. I didn't hear anything that isn't achievable and very practical. I think that it is a reason for optimism, although it may be that we're shooting too low and we need to be more hopeful and more ambitious in the transformation that we need to [achieve?] in order to get through this situation. Let's see what you all think. Yes, sir.

**Albert Geetter:**
It's been an extraordinary colloquium. I applaud you all. My name is Albert Geetter. I deal with the medical aspects of disaster management for the state of Connecticut. Dr. O'Toole, you touched tangentially on one thing which I think we need to deal with. It's an additional public health threat, and that is the dead.

**Tara O'Toole (moderator):**
The dead?

**Albert Geetter:**
We will find that if the people are dying at your hospital door or if they're dying at home and we have insufficient planning for mortuary services. By the by--I'm a retired general surgeon, so I normally don't deal with that aspect of it, we don't admit that we have them--but it is extremely important from a public health standpoint, because if we can't handle the dead, both from a biological standpoint and also from a psychosocial standpoint...this is extraordinarily important...I think we're going to face a major problem.
Diane Lapson:
Am I still pretending I'm living in Washington, or can I be myself?

Tara O'Toole (moderator):
Whatever you want to do, Diane.

Diane Lapson:
During 9/11, we had a few incidents where I was told to-I'm a community leader downtown-
I was told to please keep everyone indoors because they were bringing body parts down the street and they didn't want people to start seeing it. It was very amazing in an emergency to forget those little details that can unnerve a lot of people. I remember that day, just standing by the front door of my building, and having someone stand by the other two doors of the other two buildings, and telling people the police are doing something now, we really can't have you go outside.

This is one of the reasons I'm afraid of people being alone in their houses unless there is enough volunteers to check on everybody, because if a parent dies and the children are still there, or whatever is going to happen, we can't have a whole city full of people dying in their apartments and not being aware of how to take care of that quickly. I think it's a very serious question.

Michael Allswede:
Michael Allswede, I'm from the Strategic Medical Intelligence Research Group. I'd like to amplify Dr. Waldhorn's outstanding point on the issue of-what we're really kind of working around here is denial of care. In this scenario, as you put it out, there's 50% of the ventilators that are needed, 20% of the beds that are needed, and that's just for the flu patients. Now, there are two other groups of patients that we have to consider here, as well. We have the existing patients within the hospital, who will die if their care is diminished, intensive-care unit patients, cancer patients, etc, and we have future patients that will be sick because they'll run out of insulin, they'll have babies, they'll have other sorts of health problems, that need a hospital and access to go to.

In the middle of all this, we have a situation where probably we're going to be significantly depopulated. If you follow the SARS example, 50% of those victims of SARS in Toronto, Hong Kong, Taiwan, etc., were healthcare workers. My question here, the thing that seems to scream out to me and the thing that seems to be most important for this group to consider is, what are the rules? What do we want a hospital to be able to do, and how do we engage that dialogue with the community, given that we are really working with very finite resources? My view of the medical system [is that] it is 100% full on a normal day, is that we are a lot closer to that breakpoint than any of us would actually like to publicly admit. Dr. Waldhorn?

Richard Waldhorn:
I agree. That's why it was on my wish list that those discussions begin early and often, because they're not the kinds of decisions that can be made very effectively on the fly in
the middle of a crisis. I think the reviving the art of triage, which really has been lost in my medical training and in the training of all my trainees recently, because we haven't been faced with a real triage situation, I think it's something that we're going to have to do and begin to figure out, how do we do the most good for the most amount of people. That is going to be make some tough decisions about who gets in the front door and when do people leave the hospital, and when is care withdrawn.

I think those are the kind of ones that get a lot of attention, limitation of mechanical ventilation, etc., but I think there's another part of this, which is figuring out what can be safely deferred in medical care. Is it ok to take all the nurses out of the prenatal clinic and put them somewhere else? That sorts of make sense for a while. What kinds of procedures can be deferred? To create sort of a database of a priority list of what can be and cannot be deferred, so that you don't have to make decisions on the fly at the time of a crisis. There's a group in Canada, in Ontario, I know, that's been working on a system of maximal deferral time analysis of procedures and aspects of care. I think communities and medical specialists have to begin to work on that now.

Tara O'Toole (moderator):
I want to make sure we get in all three of these questions, so if you keep your inquiries brief, we can get you out of here on time.

Michael Dunaway:
Michael Dunaway, Chesapeake Critical Incident Partnership. I actually have a follow-on comment or a question actually. In that same comment about your observation about denial, I think you said "graceful denial of medical care." It seems to me that, kind of like that Chinese anagram that is crisis and opportunity at the same time. We have an opportunity here through the epidemic to address an issue that is looming on the horizon, that we know is coming, and that is the fact that eventually American society is going to get to a point where we have to deny care as a matter of course, because as the baby boomer generation gets farther along, medical care becomes more intensive.

What we have to deny, may have to deny in terms of influenza right now, or pandemic influenza right now, may be what we look at as a strategic problem in the long run for the nation, about what medical care do we no longer allow because we simply don't have the resources to handle the demographic problem we're going to be facing. I wonder if you'd comment on how what we're dealing with in influenza right now may mimic what we're going to deal with in the longer run in terms of medical capacity in the country.

Richard Waldhorn:
I understand the analogy you're trying to make, but I think it's a stretch, to be honest with you. I think we're far from that, at least in this country. We have rationing in this country-it's just done differently, it's done by economics, it's done by access to care, it's done in different ways. We're not without rationing now, but the type of rationing you're describing, I think-we're a ways off from that. We have more basic problems in this country. We have millions of people with no access to routine care. So, I think, we're not quite there yet. I think an epidemic, a pandemic, would force us to jump to that very
quickly, which is why I would argue that we need to think about those things now in anticipation of that eventuality.

Unidentified Audience Member 1:
One thing that you may want to consider is having a multi-faith clergy response team for the mortuaries as far as out of experience for Katrina; that's a real big issue. It plays upon different religious backgrounds on how bodies are cared for and how they are, how the rituals go in timing. That's a big issue. One real quick question. Has FEMA decided whether or not they're going to declare a pandemic a "disaster," because that would also have financial implications for the delivery systems and for the families involved.

Tara O'Toole (moderator):
I don't think FEMA is here. Does anybody in the audience know the answer to that question definitively? Sarah? This is Sarah Lister from the Congressional Research Service.

Sarah Lister:
The Congressional Research Service is trying to look at that question right now. We have no precedent either way for whether an influenza pandemic could be considered eligible for a FEMA disaster declaration. Right now, we say it's unclear, and we're proceeding with a legal analysis that may tilt one way or the other. Probably, if it were clear at this point, we'd all know about it, so I think it's unclear.

Unidentified Audience Member 1:
The closest thing you have towards it, though, is the heat deaths we had several years back, and FEMA now has heat and weather, or as far as cold and heat, as a disaster.

Jan Lane:
Tara, can I go back to the reverend's first comment with regard to a corps of folks, spiritual and pastoral counselors? We do have a model for that now with the Aviation Family Disaster Assistance Act, where there are teams that are pulled together, multi-faith counseling groups. I think the other corollary, and Diane had gotten at this earlier, is the very important need for mental health counseling, that immediate mental health counseling that would go along as a corollary to that.

Robert Tosatto:
I'll add a little bit to that. Several MRC units are actively recruiting chaplain corps within the Medical Reserve Corps specifically for that issue, and we do have a mental health working group, a national-level working group for the Medical Reserve Corps, looking at the issues of disaster mental health and what are the best models to use and to get out core competencies training to the volunteers.

Ana-Marie Jones:
Anna Marie Jones with CARD. In all the years I worked with governments and with the Red Cross and different traditional response agencies, the most common way of reaching out to businesses and non-profits was the, "Join my bureaucracy now, ask me
how, come and join, help us fulfill our mission," or to push down an unfunded mandate to do something. The things that we have not really looked at are, one, the bazillion ways there are to incentivize preparedness.

I do a lot of presenting with chambers of commerce, and the truth is, you've got businesses that spend billions of dollars to create foam fingers and rubber hats and all sorts of things, and none of the communities I serve would care whose logo is on the whistle or the flashlight or the whatever that saves their lives, so that's one piece.

The other thing is to really look at how to engage them as the solution for their own population, their own business. They come up with remarkable solutions when the context of the conversation is, "How it is that they can protect their own employees, their community, their business," and those sorts of things. So my question would be, have we looked at how we start collecting that? There are millions of ways to make this the empowered incentivized conversation as opposed to the, what we've already lived with, which actually hasn't really worked that well for us.

Ann Beauchesne:
Being from the U.S. Chamber of Commerce, I was not really playing that role. One of the things we're doing at the U.S. Chamber specifically for pandemics is reaching out to our state and local chambers, 3000 across the country. As you know, Secretary Leavitt’s gone around doing his summits. We're going to do a series of them with the Department of Homeland Security and probably CDC, bringing together the business community with the state and local chambers, one, for an education piece.

The larger multinational companies get it. They know continuity planning; they have the reserves to do that. Smaller businesses don't know what to do. Just telling them to wash their hands isn't going to cut it; we need to have steps for them to take. At the Chamber, we have a brochure up on our website now, but we're looking at model plans; we're looking at mentor programs and that kind of thing. So you're exactly right, the local and state chambers are certainly well-positioned. They know their communities, they know their people there, and you're absolutely right, we are going to reach out to all of our members.

Tara O'Toole (moderator):
Final question.

Roger Bernier:
I just really wanted to make a comment. I don't know if this is a good time before it closes, but I think one of the things that I have noticed during the day [is] that I think sometimes we're talking about public engagement fulfilling different purposes.

One of the things that I found very helpful came from Peter Sandman, who's a risk communication expert, who talked about why—this was in connection with pandemic flu—why we need the public. He gave this very easy-to-remember set of three reasons, which I would just like to put out here. You need their help, you need their advice, and you
need their buy-in. I think that really covers the waterfront. I might add a fourth, which [is that] they have a right, but that's a different issue. If you want to know why you need them, it's those three reasons that really cover the thing.

I think there's a divide in this audience between many people who are talking about public engagement because they think we need the public's help. We need their hands, we need their hands and arms, too. We need "extenders" of our capacity. I think that is not very controversial, and is very obvious in the millions of ways we might need that. We ought to be clear about all that, and that's important.

I think on the other issues, it's also important to be clear that if you're talking about public engagement-because you need their advice, or because you need their buy-in-that's a different kind of public engagement. That's getting the public because you want their ideas, because you want a sounder policy, and there's much more debate about the value of that than there is about the fact that we need the public because we need their arms and legs.

I think as we go forward in thinking about how we can make progress in promoting public engagement in disease and disaster planning and so forth, I think keeping those distinctions separate in our minds might help all of us to know which one of those kinds of public engagement purposes are we thinking about while we're having the conversation. I think we've gone back and forth between those today.

Tara O'Toole (moderator):
Thank you. I think that's a very useful conceptual distinction, and we have definitely gone back and forth, and on purpose. I wish you had said that at the beginning of the day instead of at the end. Very useful. I want to thank everybody on the panel who volunteered their help and their advice and their buy-in, in being able to participate in this panel. Thank you, all.

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**Monica Schoch-Spana, PhD**

**Closing Remarks**

Just to pick up on Roger's last comment, it was deliberate to be tacking back and forth between relying on people's advice and their investment in public policy decisions that are under way, and also relying on their arms and legs.

Because what's been interesting to watch...for individuals who've been involved in disaster mitigation from a natural hazards point of view, it's already a done deal that you have to rely on volunteers. That's been a harder lesson to sell, I think, within the medical and public health realm, because we're used to relying on highly trained professionals to help us handle health matters. [With regard to] the ethical or bioethical dilemmas on
the other hand-those tough decisions and trade-offs that have to be made-there's a sense within the medical and public health community that maybe we should be having more deliberation.

So, there are strengths coming out of folks who have more of an emergency management and disaster mitigation background, with regard to natural disasters-strengths coming out of that professional and hazards-related history, and the strengths that are coming out of the medical and public health circles, where there are difficult choices made on a daily basis with regard to care.

Some good news that I would like to leave you with is that this is not a one-off event. We will post the event proceedings online; we want to thank our co-conveners for offering to assist us in distributing knowledge of this event. We invite you and your organizations to send your members to the website to access the proceedings which will be written in a summary fashion, but also full transcripts where we have permissions from the speakers to share that broadly. Thank you to the residents of Grand Bayou for permission to share those comments.

More importantly, though, because we don't want this just to be an archived set of knowledge, and quickly forgotten-it was interesting to hear from Maggie Fox that what was news in September of last year, even though it's "old," may have to be treated again as "new news" because we've already forgotten it. So, this is not about archiving our conversations; it's about acting on our conversations today.

[In light of that point] I'd like to announce that today's proceedings will be fodder for the deliberations of a Working Group that will focus explicitly on citizen engagement and public health emergency planning. Many of the participants and speakers today are members of that working group, which will be stood up over the summer, and is tasked with issuing best principles and practices guidance in the fall—hopefully just in time for flu season.

The Biosecurity Center also intends to consult with you, our summit attendees. You decided to spend a whole day with us in pursuit of understanding the feasibility and the societal benefit of citizen engagement in a health emergency context. I think there is a lot of energy and interest and institutional momentum that can be harnessed to push this agenda further. We will be in touch with you about how we can harness our respective energies to promoting this agenda.

It's hard to summarize what transpired today, personally because I'm tired, but also because it was such a rich, rich conversation. It touched on many themes. There is a hunger within neighborhood associations and other community-based organizations, among individual citizens, and a variety of public health and public safety groups and various levels of government-an interest in this thing that we're calling public involvement. We spoke earlier about-despite there being a hunger for this sort of thing-it is a preparedness and response dimension that has unfortunately been low visibility, although that is changing.
This is not something that happens simply out of passion. There has to be thoughtful investment of time and energy and resources in making this, as Elaine put it, putting it into the DNA of our approaches to governance in today’s world. It’s not something that we add and stir, as Tara brought up before—it’s a conscious investment. This is why we're packaging this summit in terms of the concepts of disease, disaster, and democracy, where our goal is collaborative problem-solving.

I'd like to conclude the day with some thanks to some spectacular people. First, to our presenters and round table participants who gave us much, much to think about, to take back to our respective communities, and mull over and wonder how it is that we can act on all these brilliant ideas. So, thank you to all of our participants. To our attendees, thanks for your time. It was a full day, in a month that's chockfull of competing events and interests, and nice weather outside, so thanks for staying within the hotel's four walls.

Thanks to the Biosecurity Center leadership for embracing this event and footing the bill. It again speaks to the vision that comes out of a group that was conceived by our keynote presenter today, Dr. DA Henderson, and led under the visionary leadership of Dr. Tara O’Toole. My thanks to our co-conveners in helping shape the program, identifying attendees, and in the future promoting the proceedings.

And the organizers behind the scenes...because it really does take a village to pull off a conference. One can imagine what it would take to pull off the delivery of large-scale medical services. So if you will stand so that we can give you the recognition that you deserve, Andrea Lapp, who is our events planner, and got everyone here, traveled, fed, and watered; Molly D'Esopo, who designed our program and other visual delights associated with the conference; Crystal Franco and Jen Nuzzo, who were right-hand women in terms of devising the program agenda and advanced materials; to our information technology and digital gurus, Ted Priftis, Bill Boggs and Mary Beth Hansen; and lastly, but not least, the analysts who were pretty much the trouble-shooters that handled all the things that sort of fall into their laps, and they do it with great humor, Clarence Lam, Andrew Mulcahy, Allison Chamberlain, Christiana Uenza, and Jonathan Gross. Did I miss anybody? And thanks also to Mr. Bruce Campbell who signs the checks.

Thank you. We will definitely be in touch because, quite frankly, there's a lot of work to be done on this issue and we’re going to share it with all of you. Have a good afternoon.

Proceedings of the May 23, 2006 Summit: Disease, Disaster, & Democracy

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