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## Citizen Voices on Pandemic Flu Choices: A Report of the Public Engagement Pilot Project on Pandemic Influenza

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# Citizen Voices on Pandemic Flu Choices

## A Report of the Public Engagement Pilot Project on Pandemic Influenza



### Participating Organizations

Atlanta Journal Constitution  
Institute of Medicine

Georgia Department of Human Resources, Division of Public Health  
Massachusetts Health and Human Services

National Immunization Program at the Centers for Disease Control and Prevention  
National Vaccine Program Office in the Department of Health and Human Services

Nebraska Health and Human Services  
Oregon Department of Human Services

Practicum Limited

Richard Lounsbery Foundation  
Study Circles Resource Center

The Keystone Center  
University of Georgia

University of Nebraska Public Policy Center

December 2005



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## Preface

The Public Engagement Pilot Project on Pandemic Influenza (PEPPPI) described in this report was based on three premises: (1) that the formulation of vaccine policies which involve a consideration of values as well as science requires policy-makers to understand the range of society's values on the issues; (2) that the process which will best reflect society's values is a public engagement process which involves both stakeholders, including experts, and citizens with diverse backgrounds and perspectives; and, (3) that an inclusive public process which provides an opportunity for frank, open dialogue and careful deliberation will produce sounder, more supportable decisions in the short term and result in greater public trust over the longer term.

The level of public engagement or degree of interaction required to achieve meaningful dialogue and deliberation goes well beyond the focus groups, consultations, and listening sessions that are routine today. A consortium of organizations which recognized the necessity for this enhanced public input into the value laden vaccine policy decisions sponsored this project. We want to acknowledge here our gratitude to them for enabling us to carry out a project to test the feasibility and utility of enhanced public engagement on a complex health policy decision.

In the spring of 2005, gaps existed in the first Health and Human Services (HHS) Influenza Pandemic Plan and more guidance was considered desirable on how best to allocate the relatively meager supplies of vaccine likely to be available in the first months of a pandemic. To whom should it be given? To achieve what objectives?



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This report describes the convening of a representative group of stakeholders and citizens-at-large, the structure and process of stakeholder and citizen dialogues and deliberations, and the decisions made and recommendations that were developed.

At the outset of the project, some in the vaccine community feared the process could be disruptive by providing a platform for extreme viewpoints espoused by a small minority; that citizens could not be enticed to participate; that citizens would not be able to gain sufficient understanding of the technical issues surrounding pandemic influenza to offer useful advice; that the project would be a wild card added into the game of policy making around vaccines. No one who observed any of the multiple meetings of this project has described them as disruptive. Quite the contrary, most observers were surprised by the general public's interest in participating, their rapid grasp of the central issues, and their willingness to deliberate and make hard choices.

We were genuinely moved by seeing our democracy in action—seeing very diverse groups in Washington, D.C., Georgia, Massachusetts, Nebraska, and Oregon gather in table groups and engage in respectful, often passionate dialogue, knowledgeably shoulder the burden of weighing alternatives, find common ground, answer the vaccine question of interest to policy-makers, and provide their own ideas about how to best prepare for pandemic influenza.

We believe that this project has provided a much needed and timely demonstration for the vaccine community—that enhanced public engagement to address value laden issues in vaccine policy is feasible in real time and can yield useful recommendations.

To all the volunteer participants, including stakeholders, citizens, and experts who served as resource persons who gave up time with family, traveled for multi-day meetings, and bravely articulated deeply held values in a room full of strangers, we wish to express our heartfelt thanks. Your work described in this report demonstrates in concrete terms the value of our democratic ideals and beliefs, helps light the way to conduct further work on other policy challenges we face, and begins to restore the trust in government and the societal consensus needed to take full advantage of the potential of vaccines to improve public health.

Roger H. Bernier, PhD, MPH  
Edgar K. Marcuse, MD, MPH  
Co-Chairs, PEPPPI



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## Executive Summary

### Background

This Public Engagement Pilot Project on Pandemic Influenza (PEPPPI) was initiated in July 2005 to discuss and rank goals for a pandemic influenza vaccination program and to pilot test a new model for engaging citizens on vaccine related policy decisions (The Vaccine Policy Analysis Collaborative, VPACE). The Pilot Project was sponsored by a network of interested organizations listed on the cover of this report. To conduct this public consultation, the sponsors engaged stakeholders from various organizations with an interest in pandemic influenza (the National Stakeholder Group), and individual citizens-at-large from the four principal regions of the United States. The anticipated major benefits from this public consultation were the development of an improved plan to combat pandemic influenza and one more likely to gain public support, and a demonstration that citizens can be productively engaged in informing vaccine related policy decisions.

### Approaches Used

PEPPPI was carried out in five phases—two day-and-a-half dialogue and deliberation meetings with approximately 50 national stakeholders and consultants, a day-long consultation with over 100 citizens-at-large in Atlanta which took place in between the two stakeholder meetings, and three half-day sessions conducted with approximately 150 citizens-at-large in Massachusetts, Nebraska, and Oregon where citizens were shown the results of the earlier deliberations and asked for their feedback. Altogether, approximately 300 participants with diverse backgrounds and points of view came together to learn the basic facts needed to have an informed discussion about pandemic influenza, to engage in give and take discussions about potential goals for the use of limited supplies of vaccine, to weigh the tradeoffs between competing goals, and to select the goals considered most important to achieve with scarce vaccine.



### Findings

Both citizens-at-large and the National Stakeholder Group decided—with a very high level of agreement—that **assuring the functioning of society** should be the first immunization goal followed in importance by **reducing the individual deaths and hospitalizations due to influenza** (i.e. protecting those who are most vulnerable and at risk). Because of the still high importance of the second goal, the groups added that the first goal should be achieved using the minimum number of vaccine doses required to assure that function. This would allow the remaining doses to be used as soon as possible for those at highest risk of death or hospitalization. There was little support for other suggested goals to vaccinate young people first, or to use a lottery system or a first come first served approach as top priorities.



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The groups also defined the federal government's role as providing broad guidance with responsibility for more specific interpretation and implementation remaining with state and local health authorities. Both the public participants in this Pilot Project and the expert advisory bodies which deliberated separately, the Advisory Committee on Immunization Practices and the National Vaccine Advisory Committee, chose protecting society's caretakers and persons at high risk among their top priorities. However, the weight attached by the citizens-at-large and the National Stakeholder Group to "Assuring the Functioning of Society" appeared to be greater than the weight placed on this goal by the expert advisory bodies. Their joint subcommittee placed higher priority on protecting high risk persons and lower priority on most of the categories of persons responsible for assuring the functioning of society.

In addition, the PEPPPI groups developed and deemed important several recommendations related to pandemic planning. They stated the government needs to: (1) build and maintain the public's trust by decision-making that is transparent and characterized by seeking the public's input and coupled with enhanced communication and education; (2) allow the flexibility in the plan to address the unique circumstances dependent on the epidemiology of the event; (3) take action in addition to market forces to increase vaccine production capacity; (4) support the development of other public health measures to protect the public from the influenza illness; and, (5) provide resources to other regions of the world. The groups also felt it was important that the more specific decisions regarding the categories of persons to receive limited supplies of vaccine be made by health experts and not by elected or appointed representatives without public health qualifications.

## **Conclusions**

This Pilot Project provides "proof of principle" to the vaccine community that a diverse group of stakeholders and citizens-at-large can be recruited to learn about a technical subject, interact respectfully, and reach a productive outcome on an important policy question. Preliminary results from the independent evaluation of all the sessions conducted by the University of Nebraska reaffirmed this conclusion. Furthermore, the corroboration of the results of the deliberations from the four sessions involving the general public in disparate regions of the country, as well as with the National Stakeholder Group meeting in Washington D.C., gives additional weight to the recommendations. Recognition of the importance and utility of these findings was made evident in the HHS Pandemic Influenza Plan released in early November 2005 which described the agency's consideration of the priorities that emerged from the PEPPPI project. More public discussion of a similar type was called for in the HHS plan.

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## Chapter One

### **Background and Introduction**

In June 2003, the Wingspread Group, a diverse team of key stakeholders in immunization named after the site of its first meeting place, presented to the National Vaccine Advisory Committee (NVAC), a proposal entitled the Vaccine Policy Analysis CollaborativE (VPACE), outlining an enhanced framework for effective stakeholder and citizen engagement in vaccine policy analysis. The Wingspread Group urged the immunization community to move beyond traditional forms of public engagement such as public education and soliciting input at formal public hearings to create the capacity for collaborative problem solving on certain vaccination questions or decisions where different values must be weighed in addition to technical considerations.

The Wingspread Group recommendations are captured in the Final Summary Report and Proposal for the Vaccine Policy Analysis CollaborativE (VPACE) available at [http://www.keystone.org/html/pandemic\\_flu.html](http://www.keystone.org/html/pandemic_flu.html).

In order to fully demonstrate to the Centers for Disease Control and Prevention (CDC) and its broader constituency the value of conducting such collaborative group processes, members of the Wingspread Group sought an opportunity to test their new model using an important issue of immediate concern. A \$75,000 grant from the Richard Lounsbery Foundation to The Keystone Center provided the opportunity to leverage other resources and recruit partners to pilot test the VPACE approach with a current issue in immunization, namely who should be vaccinated first in the event of an influenza pandemic when supplies of vaccine are limited. Subsequent sponsors included those participating organizations listed on the cover of this report.

#### **Purpose and Outcomes**

The Public Engagement Pilot Project on Pandemic Influenza (PEPPPI) began in July 2005 with plans to forward a final report to the Secretary of Health and Human Services and other decision-makers by November 2005. It engaged citizens, local/state and federal governmental officials, academics, non-governmental organizations, health care providers, and industry representatives in deliberations about which groups in the population require the earliest protection against influenza in the event of a pandemic when supplies of vaccine are still limited. Making these difficult choices would fill a notable gap in the first U.S. Pandemic Influenza Preparedness and Response Plan released in the summer of 2004.

This Pilot Project had a dual purpose: (1) to evaluate a new mechanism for engaging the public on vaccine policy decisions; and, (2) to better inform a pending government decision by providing a ranked list of immunization goals to guide prioritization of vaccine use during a pandemic event.

## Overall Project Design

The project was designed to include both stakeholder representatives from a broad spectrum of organized and pertinent interest groups (herein called the National Stakeholder Group), as well as individual citizens-at-large not representing any organization or interest group. Both types of participants were deemed important to include to secure a broad spectrum of ideas, experiences, perspectives and values and to allow for different types of dialogue and deliberation on the issues.

Thus, the inclusion of ordinary citizens permitted a large number of individuals with no particular agendas from a broad cross-section of the population to have input that reflects what well informed Americans think about the issues. The National Stakeholder Group allowed for the full spectrum of active interest groups to bring their detailed knowledge to the table, to engage constructively in on-going dialogue, to build understanding regarding their respective interests, and to jointly problem-solve to create proposals that work to address as many interests as possible. The National Stakeholder Group also served as the body through which the input of citizens-at-large is considered and weighed before formulating any final conclusions or recommendations. Citizen Feedback Sessions in different parts of the country after the preparation of a draft report permitted a larger and more varied number of citizens to evaluate the conclusions and to provide suggestions for changes prior to final release of the report.

The Public Engagement Pilot Project on Pandemic Influenza was carried out in five phases between the five month period of July to November 2005.

<b>Phase I</b>	July 2005	First meeting of the National Stakeholder Group to frame the issue and define the project.
<b>Phase II</b>	August 2005	Deliberation day for citizens-at-large to select their highest priority goals for an influenza vaccination program.
<b>Phase III</b>	September 2005	Second deliberation meeting of the National Stakeholder Group to consider the input from citizens-at-large and to select the highest priority goals integrating all public perspectives.
<b>Phase IV</b>	September & October 2005	Feedback Sessions with citizens-at-large in Massachusetts, Nebraska, and Oregon to obtain citizen reactions to the highest priority goals and suggestions for changes to the draft report.
<b>Phase V</b>	October & November 2005	Preparation of the final report from the National Stakeholder Group on the public's perspective on the highest priority goals for a national pandemic influenza vaccination program.

The key features of the VPACE model are:

- 1) A focus on undecided science policy choices which involve both technical and values considerations;
- 2) Opportunities for independent fact-finding and balanced learning about the topic at hand from credible sources on all sides of the issue;
- 3) Inclusion as participants of both stakeholders with acknowledged interests and citizens without agendas;
- 4) Neutral facilitation;
- 5) Opportunities for both frank dialogue and genuine deliberation to take place; and
- 6) Linkage to the government decision-making process and decision-makers.

At the project's inception, a Steering Committee (members are noted on Attachment A) was convened comprising a representative cross-section of stakeholder interests related to the issue. Their role was to provide on-going guidance on process and substantive issues related to the Pilot Project.

The National Stakeholder Group sessions were chaired by Edgar Marcuse MD, MPH, Associate Medical Director, Seattle Children's Hospital, Professor of Pediatrics at the University of Washington, and a member of the Advisory Committee on Immunization Practices (ACIP) and Roger Bernier, PhD, MPH, Senior Advisor for Scientific Strategy and Innovation at the National Immunization Program, CDC.

The Institute of Medicine (IOM) under the leadership of Kathleen Stratton, PhD, hosted the National Stakeholder Group sessions and, in consultation with the stakeholders, coordinated the subject matter experts and consultants who provided balanced, independent information.

The Keystone Center and key staff members led by Mary Davis Hamlin provided neutral facilitation and overall process support to the project. In consultation with stakeholders, The Keystone Center assisted with the convening, agenda development, facilitation, logistical support and coordination of and drafting of the meeting summaries and final report.



The Local Citizen Dialogue and Feedback Sessions in Atlanta and Massachusetts, Nebraska, and Oregon were led by Jon Abercrombie and Matthew Leighninger of the Study Circles Resource Center with additional neutral facilitation by Whitney Shipley, a contractor affiliated with the Center for Biopreparedness Education at the Nebraska Medical Center.

In addition, the project secured the services of an evaluation team from the University of Nebraska Public Policy Center led by Mark DeKraai and an evaluation advisor, Miriam Wyman, a consultant with Practicum Limited, a Toronto-based consulting firm.

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## Chapter Two

### Phase I—Framing The Issues and Defining the Project

#### National Stakeholder Meeting—July 13 & 14, 2005

A complete set of meeting materials (agenda, handouts, presentations, participant list, meeting summary, etc.) can be found at [http://www.keystone.org/html/pandemic\\_flu.html](http://www.keystone.org/html/pandemic_flu.html). Selected materials—noted in the below text—are also attached to this report.

#### Approach

Approximately 50 persons including some 35 stakeholders (Attachment A) from multiple different groups with a special interest in pandemic influenza (such as health care providers, ethnic minority organizations, federal agencies, citizen advocacy organizations, and vaccine manufacturers), met twice—in July and September—to develop goals to guide immunization priorities in the event of a pandemic event. The first meeting served to better define the purposes of the project, secure essential background information, build mutual understanding regarding the values and interests important to the participants, and frame the issues for subsequent deliberation.

Harvey Fineburg, President of the Institute of Medicine, and Bruce Gellin, Director of the National Vaccine Program Office, provided keynote opening statements and introduced the Co-Chairs, Roger Bernier, and Ed Marcuse. The group's operating protocols were also reviewed, refined and ratified (Attachment B).

#### Background Information/Presentations

The Steering Committee identified a preliminary set of background information materials to provide to the Stakeholder Group to ensure informed deliberations. The presentations and speakers included:

- ◆ Basic Information About Influenza (Flu 101)—David Shay, Medical Officer, National Center for Infectious Diseases, CDC
- ◆ Standard Vaccination Policy/Assumptions during the Regular Flu Season—Bill Atkinson, Medical Epidemiologist, National Immunization Program, CDC
- ◆ Past/future Pandemics—Bill Atkinson, Medical Epidemiologist, National Immunization Program, CDC
- ◆ Vaccines in a Pandemic Influenzas Event—Alan Hinman, Senior Public Health Scientist, Public Health Informatics Institute, Task Force for Child Survival and Development, and National Vaccine Advisory Committee
- ◆ Ethical Considerations—Daniel Wikler, Mary B. Saltonstall Professor of Population Ethics, Harvard University



- ◆ Legal Considerations—Peter Jacobson, Professor of Health Law and Policy, University of Michigan, School of Public Health
- ◆ International Perspectives—Arlene King, Public Health Agency of Canada

The ethics exercise presented by Daniel Wikler was particularly compelling to the group. It helped participants grasp the nature of values dilemmas and the challenges incumbent in policy decisions involving competing values and no obvious right choice.

### Small Group Facilitated Discussions

After the initial background presentations and exercises, mixed-interest groups with neutral facilitators were asked to jointly explore the range of values and interests that they as individuals and their constituencies deem important to guide immunization priorities. They were provided a handout with illustrative values, goals, and population subgroups to support their discussion (Attachment C). In addition, they wrestled with the questions below:

- ◆ How comfortable are you considering prioritization decisions not based on “protect the most vulnerable?”
- ◆ What is important to you about any ranking?
- ◆ Why is this task particularly troubling in light of your personal beliefs and things you and your constituency cherish?
- ◆ What would you need to hear (if anything) before you changed your mind?
- ◆ What are your deepest concerns about determining vaccination priorities?

The outcomes from these small group discussions were shared in the plenary and built the foundation for framing the deliberations of subsequent sessions.

Below are three dilemmas posed to the participants:

#### Example 1:

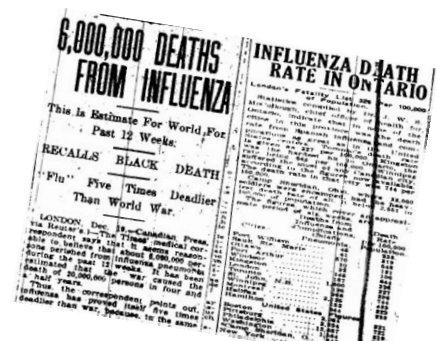
You are chief of a ward with 100 patients. 50 of these patients need 2 pills to survive. One pill does not help them. 50 of these patients need 1 pill to survive. You have 50 pills. You can't get more. Who should get the pills? On what basis should they be chosen?

#### Example 2:

Five children are playing on a trolley track as the trolley approaches. If the trolley is diverted to a spur, their lives will be saved; but one child is playing on the spur. The driver has a heart attack. You would be able to divert the trolley. Should you do so?

#### Example 3:

You are a surgeon with five patients who need 5 organs. You could harvest one healthy patient and save all 5. Should you?



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## Chapter Three

### Phase II—Getting Citizen Input

#### Atlanta Citizen Dialogue Session—August 27, 2005

A complete set of meeting materials (agenda, handouts, presentations, participant list, can be found on the website at [http://www.keystone.org/html/pandemic\\_flu.html](http://www.keystone.org/html/pandemic_flu.html). Selected materials—noted in the below text—are also attached to this report.

#### Background Information

On Saturday August 27, 2005, 101 citizens participated in an all-day public engagement event at the Loudermilk Center for the Regional Community in downtown Atlanta. The participants were a diverse representation of gender, age (adults from 18 to 78) and ethnicity. Fourteen tables of participants were supported by volunteer facilitators as well as technical experts from multiple private and public organizations, including cadres from the University of Georgia and CDC.

The Study Circles Resource Center provided lead process design and facilitation services for the event, including drafting a discussion guide which structured the deliberations of the day.

KIDazzle Child Care & Learning Center in downtown Atlanta donated day care services. Free, convenient parking, and onsite meals encouraged maximum attendance and eased the cost and logistical burdens of participating.

#### Welcome and Charge To The Citizens

The participants were welcomed by Dr. Steve Cochi, Acting Director of the National Immunization Program (NIP); Dr. Roger Bernier, Senior Advisor in NIP and Co-Chair of this Public Engagement Pilot Project on Pandemic Influenza; Mr. Chris Hinton, Honorary Citizen Participant, an Atlanta area businessman, and former Atlanta Falcons football player; and Ms. Sarah Landry, Associate Director for Policy in the National Vaccine Program Office at the Department of Health & Human Services (HHS).

Dr. Bernier gave the group its charge: Rank in priority order a list of potential goals for a national pandemic influenza vaccination program. **These potential goals were:**

- (1) Save those most at risk**
- (2) Put children and young people first**
- (3) Limit the larger effects on society**
- (4) Use a lottery system**
- (5) Use the principle of "first come, first served"**



## Presentations and Exercises

Dr. William Atkinson, Medical Epidemiologist, National Immunization Program, CDC, provided background information to the citizens and fielded questions from the group on influenza disease/vaccine and on past/future pandemics. Citizens were also given a handout pre-reviewed by experts containing all the essential facts about influenza entitled “20 Answers You Need To Know.”

Participants carried out an ethics dilemma exercise constructed by Harvard ethicist Daniel Wikler and modified by Emory University ethicist Kathy Kinlaw. The exercise surfaced the underlying values which could serve as the drivers for the choices to be made later in the day about vaccination goals.

## Dialogue and Deliberation

Participants engaged in collaborative discussions in the early afternoon to identify and weigh the tradeoffs among the different goals for a national pandemic influenza vaccination program. At the end of the deliberations, each of fourteen table groups selected their highest ranked goal by placing three dots next to the most favored goals on the list of five. Participants were free to place all of their dots on their first choice or could distribute their dots across two or three goals.

Ten of the fourteen tables selected the goal "limit the larger effects on society" as the most important. Four tables selected "save those at highest risk" as the most important goal. Overall, the ranking was as follows:

- 133 “dots” Limit the larger effects on society
- 104 “dots” Save those most at risk
- 29 “dots” Put children and young people first
- 18 “dots” Use a lottery system
- 4 “dots” Use the principle of "first come, first served"

In the final plenary session, the lead facilitator asked the citizens group as a whole if they would vaccinate all of society’s caretakers first, or allocate some proportion of the limited vaccine supply to save those at high risk. The majority of persons who raised their hands were in favor of splitting the available vaccine.

During the plenary discussion, some citizens stated they were uncertain that they could trust government to pay attention to the results of their deliberations. This uncertainty was initially expressed in some of the smaller table group discussions. The newspaper article published after the meeting described the concern citizens had and stated that “some of them left the meeting skeptical that their efforts would make much difference.”

The final afternoon session involved participant brainstorming on actions needed to prepare for an influenza pandemic. Participants stressed the need for a proactive, comprehensive U.S. pandemic

influenza plan, which should include an immediate education and communication campaign. Participants reported that this campaign should provide the public with timely information on pandemic influenza issues, as well as information on general hygiene and ways to prevent influenza transmission.

Citizens also suggested that the number of influenza manufacturers should be increased to produce a more adequate supply of vaccine in the U.S.

Among the innovative ideas suggested was the creation of a TV reality show depicting "real-time" government and citizens preparations for the pandemic. Another idea was to reinstitute the Red Cross Home Nursing course to alleviate some of the burden on hospitals that may result from an influenza pandemic. It was also suggested that pandemic influenza public health messages be included in electric and water bills, bank statements and grocery bags.

### Final Sessions

The final session of the day gave the participants an opportunity to indicate their own personal degree of agreement with the group's goal ranking as previously noted. Using a scale of 1-10 with the higher numbers indicating a stronger degree of agreement, at least 87% of the participants (N=72) rated the strength of their agreement with the outcome at 8 or above on this scale.

Participants also recorded their individual ranking of the goals. The results of this survey showed that the goal to "limit the effects on the larger society" received 65 first priority rankings, 12 second place, and very few below that level. The goal to "save those most at risk" received 11 first priority rankings, 59 second place, 8 third place, and very few below that level.

### Media Coverage

Media coverage for the event included articles about the meeting in the Atlanta Journal-Constitution (AJC) on the day before and the day after the meeting (Attachment D). Factual errors were made in reporting the goal rankings which were reflected in a misleading headline and in the total number of attendees. On August 31, 2005, the reporter and the public editor for the newspaper acknowledged the factual errors and published corrections. As Co-Chair of the Pilot Project, Dr. Bernier also wrote a letter to the editor of the AJC to make clear that the results of the citizen deliberations were recorded correctly by the organizers and would be accurately transmitted to decision-makers.

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The persons from these organizations were observers:

CDC Office of Health Communications  
 CDC Office of Public Health Partnerships  
 CDC Office of Strategy and Innovation  
 CDC Office of Surveillance  
 Middle Tennessee State University  
 Massachusetts Department of Health  
 Oak Ridge Institute for Science and Education  
 The Human Resources and Services Administration  
 The National Vaccine Information Center  
 The Public Health Agency of Canada  
 The Swedish Institute for Infectious Disease Control  
 Wisconsin Women's Network

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## Chapter Four

### Phase III–Getting Stakeholder and Citizen Input Combined

#### National Stakeholders Meeting II–September 7 & 8, 2005

A complete set of meeting materials (agenda, handouts, presentations, participant list, etc.) can be found on the website at [http://www.keystone.org/html/pandemic\\_flu.html](http://www.keystone.org/html/pandemic_flu.html). Selected materials–noted in the below text–are also attached to this report.

#### Background Information

In September, the National Stakeholder Group received additional informational handouts and presentations in response to the group’s earlier requests for supplementary data. Two citizen participants from the Atlanta Dialogue Session also provided an overview of the outcomes from their meeting as well as personal insights about participating in that event. The other presentations included:

- ♦ FEMA/Homeland Security Critical Services Designations Update–Marion Warwick, U.S. Department of Homeland Security
- ♦ How Might a Lottery Work?–Logistical/Feasibility Considerations, Jeff McMahan, Department of Philosophy, Rutgers University
- ♦ County Perspective from Last Year’s Flu Vaccine Rationing–Carol Jordan, Senior Health Care Administrator, Montgomery County Maryland Government
- ♦ Public Behaviors in a Crisis–Monica Schock-Spana, Center for Biosecurity, University of Pittsburgh
- ♦ Additional Considerations Regarding Pandemic Influenza–Michael Osterholm, University of Minnesota, School of Public Health
- ♦ ACIP’s Proposal Regarding Vaccination Priorities–Dr. Steve Cochi, National Immunization Program, CDC (Attachment E)

Monica Schock-Spana’s presentation of evidence which debunked commonly held myths about disasters provided rich information for subsequent discussions by the group. Her full presentation is included as Attachment F. A summary of the myths is also listed below.

- ♦ MYTH #1: Disasters are equal opportunity events; they happen in random and in quirky, but essentially democratic ways.<sup>1</sup> Hurricanes, outbreaks, heat waves, earthquakes, and chemical spills kill indiscriminately. They do not care “who” the victim is.
- ♦ MYTH #2: Whether people comply with evacuation plans, isolation and quarantine, or other public health and safety orders, is strictly a matter of “personal choice.”
- ♦ MYTH #3: When life and limb are threatened on a mass scale, people panic. They revert to their savage nature, and social norms readily break down.
- ♦ MYTH #4: Command-and-control is the most effective management approach to an “emergency.” Centralized, insular decision-making and authority structures among trained professionals guarantee the least harm to people and property. Ordinary civilians and everyday institutions are inadequate to deal with crises.
- ♦ MYTH #5: Acts of God and Nature are pre-ordained. There is no real way to thwart their ultimate outcome. The same goes for Bureaucratic Red-Tape, another so-called immutable force.

<sup>1</sup>Walter Peacock. *Consequences of Disaster Myths*, 30th Annual Hazards Research and Applications Workshop, Boulder, CO, July 12, 2005.

## Small/Large Group Facilitated Discussion

The stakeholders were organized into several mixed interest groups to weigh the advantages and disadvantages of an initial list of possible goals for a national pandemic influenza vaccination program. (Attachment G). The small groups considered:

- ♦ What are the underlying values for each goal?
- ♦ What are the potential value tradeoffs for each goal?
- ♦ What are the implications of a goal's implementation (such as who would be vaccinated or not be vaccinated) and other consequences or concerns?

Below is the illustrative list of goals used to initiate the small and large group discussions. Refer to Attachment H for a summary of the group's discussion of each goal.

### POTENTIAL GOALS USED TO INITIATE DISCUSSION

- #1. Give everyone an equal chance to be protected.
  - A. Lottery
  - B. First come, first served policy
- #2. Protect persons with the most life ahead of them.
- #3. Seek to protect those of any age or health condition most or more likely to die from a new influenza strain.
- #4. Assure public safety.
- #5. Maintain emergency and/or life saving services.
- #6. Protect society's key government leaders and decision-makers.
- #7. Protect those providing the most critical services which keep society running.
- #8. Provide some vaccine to other countries even if it is at the expense of vaccinating some persons in the United States.
- #9. Protect those who provide homeland security and those who defend us against military threats abroad.
- #10. Assure vaccine production.

After an in-depth discussion of the potential goals, the group, using a ranking exercise coupled with additional large group negotiations, developed the following framing and ranking of goals to guide vaccination policy during a pandemic influenza event.

## **STATEMENT OF CITIZENS AND STAKEHOLDERS ON PRIORITIES FOR THE USE OF PANDEMIC INFLUENZA VACCINE**

### **Hierarchy of Goals**

**#1** Assure Functioning of Society.

**#2** Reduce Individual Deaths and Hospitalizations Due to Influenza.

#### **Process:**

The group recognizes that the federal government will provide only broad guidelines and that specific decisions about who to vaccinate will be made at the local level (state and local health departments, specific facilities).

#### **#1. Assure Functioning of Society:**

- ♦ Assure production, distribution and administration of vaccines (includes manufacturing, workers associated with vaccine clinics, etc.).
- ♦ Maintain emergency response and life saving services.
- ♦ Assure provision of other critical services. This might include but is not limited to: public safety and maintaining law and order; protecting society's key government leaders and decision-makers; maintaining homeland security, utilities, food distribution, and communications.

#### **#2. Reduce Individual Deaths and Hospitalizations Due to Influenza:**

- A. Protect those most or more likely to die from a new influenza strain, as defined by ACIP/ NVAC recommendations, unless the emerging epidemiology of pandemic influenza defines new risk groups.
- B. Healthy persons 2 to 64 years old not in other groups.

**Assumptions:** The preceding statement was developed within the context of the assumptions below.

- (1) There will be a limited supply of vaccines in the early days of the pandemic, therefore prioritizing who receives the limited supply is important.
- (2) The government will buy all the vaccine supply and distribute it at the same time to all states across the country based on population size (while remaining flexible enough to address considerations such as seasonal population fluctuations etc.).
- (3) The group based their recommendations not on a mild or worst case scenario but on a moderately severe pandemic as described in Trust for America’s Health Report, “A Killer Flu?,” which anticipates half a million deaths and two million hospitalizations.
- (4) All age groups will be attacked equally by the virus; however, death and hospitalization rates most likely will be highest in infants under 1 and persons 65 and older as occurs with annual influenza epidemics.
- (5) Based on mathematical modeling work done by Martin Meltzer, CDC, probably no more than 10-15% of the workforce will be out sick or taking care of a sick relative on any one day during the peak of the pandemic.
- (6) The goal of the vaccine is to protect the persons to whom it is given or their close contacts and not to decrease transmission in the general population—there will not be enough vaccines available to adopt a strategy to effectively reduce transmission.
- (7) Vaccine is used only in persons for whom it works well and priorities will not be based on anticipated life expectancy.

## **Additional Recommendations**

### **Allocation**

The three statements under the first goal, “Assure the Functioning of Society,” should be viewed as an articulation of the key societal functions that need to be maintained, not categories within which all service providers would be vaccinated. Further, the Stakeholder Group considered the functions in the first goal as equally important, therefore, crucial individuals related to each function would be vaccinated simultaneously—not sequentially. The amount of doses allocated to the first goal will depend on the severity of the pandemic but regardless should be based on the minimum number doses required. If “Assuring the Functioning of Society” does not require a large allocation of doses, then the second goal, “Reducing Individual Deaths and Hospitalizations Due to Influenza” will receive an allocation of vaccine doses sooner.

### **Flexibility**

Any plan intending to address a pandemic event needs to remain flexible in order to respond to implications of the epidemiology and severity of the event. Effective planning will also require a greater understanding of the public health infrastructure at the state and local levels to inform what will really be needed to keep society functioning. The group noted the need to develop trigger points, or key metrics, to guide the proportional allocation between the two primary goals. The group also recommended the need to create a model and plan around the most severe potential scenario such as the 1918 event.



### **Federal Government Role**

The Stakeholder Group noted that it is the federal government's role to provide broad guidance but that state and local authorities should be responsible for interpreting them at a more detailed level. The group urged the CDC to work with the National Governors Association to assess individual states' assets relative to their ability to respond to a pandemic event. A multi-sector approach (state and local governmental agencies, non-governmental organizations, business, special needs and disadvantaged populations) must be taken in planning and education efforts.

### **Building Production Capacity**

Although the group recognized the inevitable shortage of vaccines early in a pandemic event, they stressed the imperative of enhancing production capacity. The group noted that enhancing production capacity will require government intervention and investment as opposed to relying on the market system alone.

### **Building and Maintaining Trust: Transparency/Communication/Education**

Building and maintaining trust with the public is crucial. The government's actions in preparation for and during the pandemic event must be transparent and responsive to citizens' needs, concerns and input. The Stakeholder Group urged that decisions need to be made by appropriate experts and not within the political arena. Early and clear education about the characteristics and implications of a pandemic event is important—particularly focused on how it will differ from a regular flu season. The public will also need to understand the inevitable limits to vaccine supply in the early days of the pandemic. The group urged the government to apply lessons learned from the recent small pox experience. For example, a national credible spokesperson should be named to support the educational effort. It is also essential to carefully explain why children as a group are not specifically named as a priority vaccination goal—e.g. the group believed that the best way to safeguard the well-being of children in such an event is to ensure societal functioning. Finally, the group felt that it will be important to obtain commitments from vaccinated individuals stating that they will conduct the work for which they received the immunization.

### **International**

The group believed that any national pandemic plan should include providing resources to other regions of the world, particularly to support early detection, containment, and participating in global alliances to increase global production capacity. The group specifically noted that the United States needs to assist the World Health Organization in its global efforts.

### **Multi-pronged Approach**

A full range of tools and strategies in addition to vaccination should be planned for and employed by the government during a pandemic event.



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## Chapter Five

### Phase IV—Citizens’ Reactions To Vaccine Priorities

#### **Feedback Sessions in Massachusetts, Nebraska, and Oregon on September 17, 24, and October 1, respectively.**

Approximately 40 citizens-at-large from Massachusetts, 85 citizens from Nebraska, and approximately 40 citizens from Oregon met on successive Saturdays in mid-September and early October 2005. After hearing a presentation from a local epidemiologist and/or an infectious diseases expert and asking questions to learn the essential facts about influenza, participants were informed about the highest priority goals selected and the conclusions reached by the National Stakeholder Group which deliberated in Washington in July and September 2005. The citizens were organized into table groups which then brainstormed around these goals to identify their reactions. Following a presentation and a group discussion of the goals, the groups were asked if they concurred with the goals as stated or whether they wished to see changes in the goals statement. The facilitator then determined the degree of support for any proposed changes.

**In Massachusetts**, the citizens concurred with “Assure the Functioning of Society” as the first and “Reduce Individual Deaths and Hospitalizations” as the second priority goal. This concurrence was obtained after it was explained to the citizens that assuring the functioning of society would be accomplished by using only the minimum number of doses necessary, and thereby allowing the remaining vaccine to be used to target the second priority goal (specifically, to protect high risk individuals) as soon as possible.

Citizens also stated that the number of different types of services considered critical to achieve the first priority goal could be reduced from the list presented, and that not all persons employed in the critical services categories would need to be vaccinated to assure the functioning of society. In this context, assuring the functioning of society is assumed to mean assuring the functions most essential to saving or protecting lives directly at the front lines of service, and not to mean all societal functions needed to keep society functioning optimally or even normally.

Examples of other potentially useful ideas which emerged from the session with Massachusetts citizens were that consideration would have to be given to protecting the family members of persons judged to be critical service providers, and that transparency and open communication with the public about all aspects of the pandemic planning would be important to assure the fairness and trust essential to the plan’s success.

See Attachment I for more details.

**In Nebraska,** approximately one half of the citizens present concurred with the statement of goals as written and this agreement appeared to be because the citizens trusted state and local government decision-makers and appreciated the flexibility which the statement would afford them. The remaining half of the citizens identified five potential changes in the statement—the proposed change which received the most support was the proposal to modify the wording of the statement to make it more clear that the high risk groups would be identified based on the emerging epidemiology of influenza at the time of the pandemic and not based on the traditional high risk groups as identified by the ACIP and the NVAC.

The other proposed changes had only limited support. Examples of these other ideas were: (1) a proposal to rework the priority groups to include students and teachers and to set aside a small percentage of the vaccine for a lottery so that those persons without any claim to the vaccine initially might nevertheless retain some hope of being vaccinated; (2) a proposal to create guidelines for adjusting the implementation of the vaccination program if there is public panic or other social disorder; and, (3) a proposal to further define who is expected to be in the group of those most likely to die.

Agreeing with Massachusetts, citizens proposed the need to give clear advice on how to protect against influenza to persons who are not likely to get vaccinated because they are not on the list of priority groups.

See Attachment J for more details.

**In Oregon,** almost all of the citizens who participated in the feedback session concurred with the priority goals described in the statement but wanted to see some changes made. They agreed with citizens in Nebraska and Massachusetts in calling for better definition of who would be eligible for vaccination in the first priority category and they were strong in their desires to have the decisions about vaccination priorities made by public health experts rather than by political appointees. Also, Oregonians were interested in exploring strategies which could protect people by limiting people's exposure to influenza by means other than vaccination.

An example of another important warning to emerge from the Oregon citizen session—that was also expressed in other states—was the need to have a lot of education and training for the public if vaccine priorities are to be made public. The anticipation is that people will not respond well to being left out of the vaccination program without advanced education and training.

See Attachment K for more details.



## Proposed Changes to the Findings and Recommendations of the Citizens and Stakeholders

All three Feedback Sessions agreed with the Atlanta citizens-at-large and with the National Stakeholder Group's goal rankings for vaccine allocation during a pandemic event. The Feedback Sessions were not provided with the Stakeholder Group's "Additional Recommendations." Therefore it is even more compelling that the Feedback Sessions also wanted to forward additional recommendations to decision-makers and to note how similar their recommendations are to those from the National Stakeholder Group. The Stakeholder Group reviewed and discussed the key themes from the Feedback Sessions and adopted them as part of their final recommendations with certain caveats.

All of these proposed changes (with the exception of bullet 1) have been incorporated into the findings and recommendations of this report:

1. Reduce the number of different types of services considered critical to "Assure the Functioning of Society" in goal one by identifying those categories most essential to saving or protecting lives at the front lines of service. *The Stakeholder Group agreed in principle with the above statement but noted that the specific task is outside of their scope of work.*
2. Clarify that not 100% of all person in each critical category in goal one needs to be vaccinated to "Assure the Functions of Society."
3. Clarify that the high risk groups to be vaccinated during a pandemic should be based on the epidemiology of the pandemic event.
4. Request that the decisions about which population groups are priority groups should be made by appropriate experts and not within the political arena.



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## Chapter Six

### Evaluation Results

The PEPPPI project contracted separately for an independent evaluation with the University of Nebraska Public Policy Center and with a public engagement expert from Practicum Limited, a Toronto-based consulting group. The results of the preliminary evaluation were available in December 2005 at the time this report was completed and a more comprehensive evaluation will be reported at a later date. Below are the key findings from the preliminary evaluation for each of the main goals of the PEPPPI project. Overall, the evaluators found that the PEPPPI was largely successful in meeting its multiple process-related goals (see below). A more detailed presentation of the methods and results of the process evaluation, including many illuminating comments from the participants in the multiple sessions, are included in Attachment L of this report.

#### Overview

#### Participation and Representation

##### **Goal 1a: Attract citizens to participate in the process in four locations: Georgia, Massachusetts, Nebraska, and Oregon.**

Preliminary results and observations indicate the process was successful in attracting citizens to participate in the process with good attendance at the meetings: 101 in Atlanta, Georgia; approximately 40 in Massachusetts; 85 in Omaha, Nebraska; and 35 in Portland, Oregon. Many citizens indicated they were motivated to participate primarily through civic duty or an interest in the topic.

##### **Goal 1b: Recruit participants who reflect a diversity of perspectives, and with varying demographic characteristics such as age, gender, race/ethnicity, and education.**

The demographic information of Atlanta, Boston, Omaha, and Portland participants indicates the groups were diverse based on age, gender, race/ethnicity, and education, although they may not have reflected the general population. Participants included a larger number of persons who were in the 55 – 64 age category, more females than males, and had higher education levels than the general population. Observers and citizens perceived that there was good diversity in perspectives and political views, although some noted that persons who were poor were not well represented.

#### Knowledge of Participants and the Dialogue and Deliberation Process

##### **Goal 2a: Provide information to participants so they have sufficient knowledge about pandemic influenza to adequately consider and discuss the issue of the prioritization of pandemic influenza vaccination and potential goals for a vaccination program.**

The process designed by the project organizers was successful at increasing citizens' knowledge levels. Results indicate citizens participating at all four locations significantly increased their knowledge after receiving information about pandemic influenza and participating in the deliberations. Survey results

indicate the D.C. Stakeholders had a relatively high level of knowledge about pandemic influenza before engaging in the deliberative process or receiving information at the meeting. Further, stakeholders and citizens believed they had enough information to have well-informed opinions about vaccine allocation.

**Goal 2b: Design and implement a process that promotes a balanced, honest, and reasoned discussion of the issues while respecting diversity of views.**

The preliminary results indicate stakeholders and citizens generally believed the process was of high quality. Results indicate that participants at all six meetings felt comfortable talking, felt that others felt comfortable talking, and thought the discussion was fair to all participants. Respondents at all locations tended to believe that the process produced credible, relevant and independent information. Participants indicated that the discussion was balanced and that no one person or group dominated the process. There was less agreement about whether important points were left out of the discussion; participants in the shorter Boston, Omaha and Portland meetings felt important points were left out. Observers generally perceived that the high quality facilitation resulted in the balanced deliberation.

**Goal 2c: Provide a forum for citizens to deliberate and consider multiple points of view. The evaluation tests the assumption that deliberation affects the opinions and judgments of participants related to prioritization of pandemic influenza vaccination.**

Citizens at all four locations tended to believe that the process helped them understand trade-offs. Pre and post-survey results indicate that citizens and stakeholders changed their opinions about social values, goals and priority populations as a result of the process.

**Value of Citizen Participation and Overall Value of the Consultation**

**Goal 3a: Citizens contribute useful information for the stakeholder deliberations, and stakeholders consider and integrate citizen input into their recommendations.**

Responses from stakeholders regarding how they considered citizen input were mixed. Most stakeholders who were interviewed indicated they considered the citizen input very seriously. Others, however, indicated that the citizen impact did not have a great deal of influence.

**Goal 3b: Citizen and stakeholder input receives serious consideration by decision-makers and adds value to the input already being received from expert groups. A key aspect of the evaluation is to understand how citizen and stakeholder input is used by decision-makers in establishing pandemic influenza vaccination priorities.**

This goal was not formally assessed in the first phase of the study by the evaluation team but will be reported later.

A preliminary assessment of the utility of the consultation can be gleaned from the statements made in the HHS Pandemic Influenza Plan in November 2005 about the PEPPPI initiative. They indicate



HHS interest in the goal accorded the highest priority by the citizens-at-large and the National Stakeholder Group, but ranked lower by the HHS expert advisory bodies, namely “Assuring the Functioning of Society”.

According to the HHS Plan, “Advisory Committee recommendations are presented in this report to provide guidance for planning purposes and to form the basis for further discussion of how to equitably allocate medical countermeasures that will be in short supply early in an influenza pandemic.

Two federal advisory committees, the Advisory Committee on Immunization Practices (ACIP) and the National Vaccine Advisory Committee (NVAC), provided recommendations to the Department of Health and Human Services on the use of vaccines and antiviral drugs in an influenza pandemic.



Although the advisory committees considered potential priority groups broadly, the main expertise of the members was in health and public health. The primary goal of a pandemic response considered was to decrease health impacts including severe morbidity and death; secondary pandemic response goals included minimizing societal and economic impacts. However, as other sectors are increasingly engaged in pandemic planning, additional considerations may arise. The advisory committee reports explicitly acknowledge the importance of this—for example highlighting the priority for protecting critical components of the military. *Finally, HHS has recently initiated outreach to engage the public and obtain a broader perspective into decisions on priority groups for pandemic vaccine and antiviral drugs. Though findings of the outreach are preliminary, a theme that has emerged is the importance of limiting the effects of a pandemic on society by preserving essential societal functions...* [Emphasis added]

### Citizen and Stakeholder Satisfaction

**Goal 4a: Citizens are satisfied with the process and believe their input will be considered by decision-makers.**

There was agreement by stakeholders and citizens that the process produced a positive outcome. Stakeholders and citizens at all sites also generally agreed that decision-makers would consider their input—although this belief was not strong. Stakeholder and citizens believed that the process would increase the public’s support of the decision ultimately made.

**Goal 4b: As a result of the process, the relationships among participating stakeholders improve.**

Most stakeholders thought that the process had changed their relationship with other stakeholders. These changes included strengthening the relationships, creating a better understanding of each other’s thoughts and priorities, bringing stakeholders closer together, and creating relationships that did not exist prior to the process.

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## Chapter 7

### Summary and Conclusions

The Public Engagement Pilot Project on Pandemic Influenza (PEPPPI), a public consultation, successfully conducted multiple dialogue and deliberation sessions involving approximately 300 citizens and stakeholders in different parts of the United States. Participants with diverse backgrounds and points of view came together to learn the basic facts needed to have an informed discussion about pandemic influenza, to engage in give and take discussions about potential goals for the use of limited supplies of vaccine, to weigh the tradeoffs between competing goals, and to select the goals considered most important to achieve with scarce vaccine. In all parts of the Pilot Project, participants decided with a very high level of agreement that “Assuring the Functioning of Society” should be the first goal and “Reducing Individual Deaths and Hospitalizations Due to Influenza” should be the second priority goal. The first goal is to be implemented using the minimum vaccine necessary to assure the functioning of society and, once assured, using the maximum number of doses possible to reduce individual deaths and hospitalizations due to influenza. There was little support for other goals to vaccinate young people first, or to use a lottery system or a first come first served approach as top priorities.

The consistency of the results of the deliberations in four separate populations of diverse citizens from the four principal regions of the United States and the consistency of the results between citizens at large and the group of stakeholders representing the major organizations or sectors with a strong interest in influenza give considerable weight to the findings even though the number of participants was still relatively small. According to Daniel Yankelovich, a public engagement expert, a principal outcome from public engagement is determination of “the boundaries of political permission.” It seems clear from the Pilot Project what these boundaries are for decision-makers and technical experts.

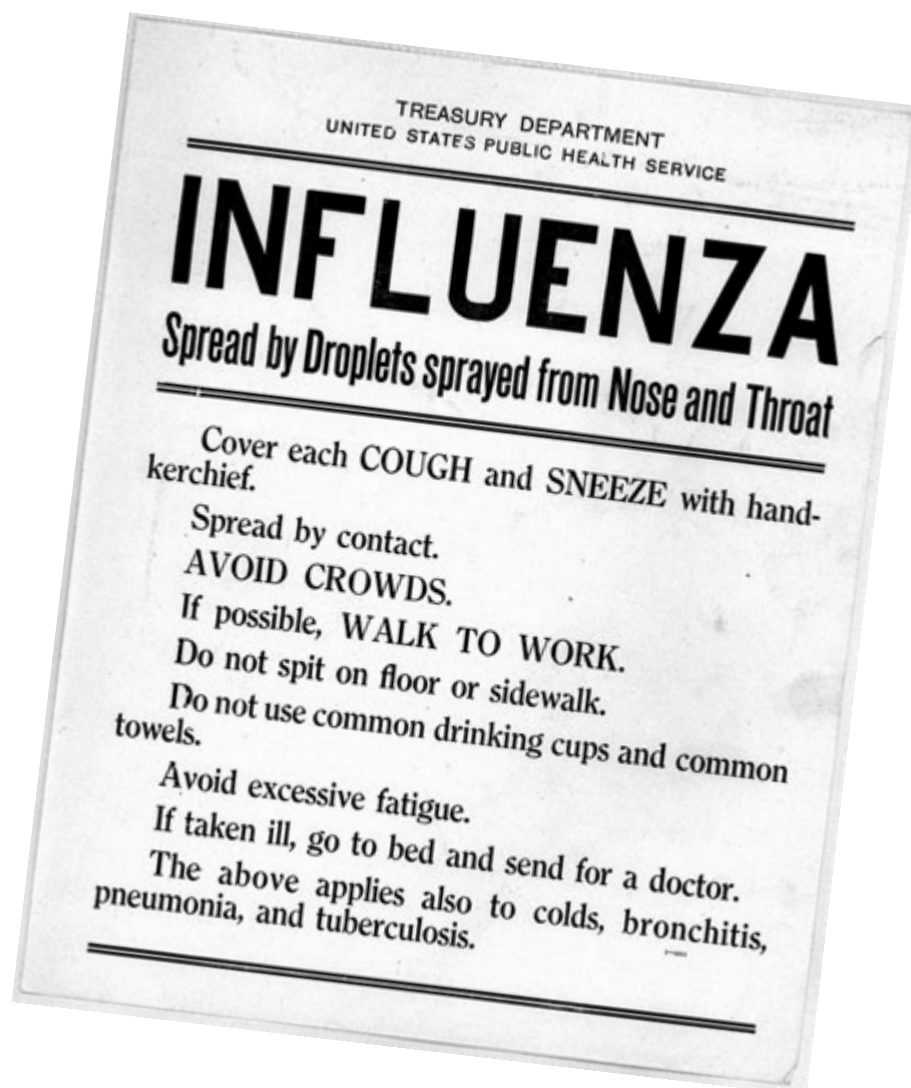
Both the public participants in this Pilot Project and the expert advisory bodies, the Advisory Committee on Immunization Practices and the National Vaccine Advisory Committee, chose protecting society’s caretakers and persons at high risk among their top priorities. However, the weight attached by the public to “Assuring the Functioning of Society” appeared to be greater than the weight placed on this goal by the two advisory bodies which placed higher priority on protecting high risk persons ahead of most of society’s caretakers.

The soundest policy may require further elaboration on how both of these goals can be pursued together. Perhaps the public’s concept of “Assuring the Functioning of Society” but using the minimum number of doses necessary to do so at the discretion of state and local public health officials has the potential of including the most categories of persons deemed critical to the functioning of society while at the same time being able to conserve as many doses as possible for high risk persons.



This Pilot Project has provided “proof of principle” that a diverse group of stakeholders and citizens-at-large could be recruited without financial incentives to learn about a technical subject, interact respectfully in give and take discussions, and reach a productive outcome by ranking goals related to the use of pandemic influenza vaccine as charged by the organizers. The degree of public engagement that was achieved was at a higher level of interactivity than what is normally achieved in vaccine related decision-making in the United States and showed that this higher level of public or citizen engagement is possible. Other pending vaccine policy questions which involve considerations of both facts and values, such as strategies for the use of the new human papilloma virus vaccine, may be good candidates for enhanced public engagement to help inform future decision-making.

A fuller assessment of the potential benefits from this Pilot Project is still underway and potentially important findings will be reported at a later date.



## Attachments

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## Attachment A: National Stakeholder Group Participants



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\*The representatives on this list were appointed to the National Stakeholder Group either because of their affiliation with their respective organization or because of individual expertise; however, it cannot be assumed that the stakeholder recommendations in this report were made with the full understanding and support of their organizations. Not all of the stakeholders listed were able to attend both meetings.

## Attachment A: National Stakeholder Group Participants (continued)

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## Attachment B: Operating Protocols

### Draft Operational Protocols

#### Pandemic Influenza Vaccination Prioritization Public Participation Project National Stakeholder Group (July 7, 2005)

#### I. Purpose/Outcomes

There are many important policy questions related to pandemic influenza planning, however, the focus of this project is on the narrow question of priorities for the use of influenza vaccine.

##### OUTCOME 1:

- a. Develop a ranked list of immunization goals to guide prioritization of vaccine use during a pandemic event.
- b. Conduct and document a rich discussion of stakeholders' and the public's underlying values/principles and interests related to the ranked goals; and
- c. To the extent possible—reference the work of other groups' recommendations regarding sub-populations designated under specific goals, determine the degree to which the recommendations resonate with the values and interests expressed by participants in this effort, and if necessary make alternative recommendations regarding sub-populations for specific goals.

##### OUTCOME 2:

Pilot test several approaches to engaging the public to determine their efficacy and usefulness in informing wise decision-making in the health policy arena.

#### II. Overall Project Design

The project is designed to engage stakeholder representatives from a spectrum of organized and pertinent interest groups (The National Stakeholders Group), as well as the general public (Local Citizen Dialogue and Feedback Sessions), comprised of individual citizens not representing any organization or interest group. Both types of participation are important to include because each has a different set of experiences and perspectives to contribute, each may value differently the tradeoffs in proposed solutions to problems, and both must support any decisions made if policy implementation is to succeed.

##### NATIONAL STAKEHOLDER MEETINGS

Below is a summary of interest categories included in the National Stakeholders Group and general logistical information:

- ◆ Non-governmental organization which represent the range of interests related to pandemic flu events and vaccine priorities;
- ◆ Government agencies and their advisory committees involved with vaccines;
- ◆ Health care workers and provider organizations;
- ◆ Vaccine industry representatives;
- ◆ State and local government agencies;
- ◆ Minority group organizations;
- ◆ Emergency preparedness and bioterrorism professionals; and
- ◆ Private health insurers.

## **Attachment B: Operating Protocols (continued)**

### **Meeting I—Institute of Medicine, Washington D.C.**

July 13, 2005            8:00 AM–5:00 PM

July 14, 2005            8:00 AM–3:00 PM

### **Meeting II—Institute of Medicine, Washington D.C.**

September 7, 2005    8:00 AM–5:00 PM

September 8, 2005    8:00 AM–3:00 PM

## **LOCAL CITIZENS DIALOGUE AND FEEDBACK SESSIONS**

Participants from the general public will be chosen from the four principal areas of the United States, the North, South, Mid-west, and Western regions and will plan to include at least 100 citizens. The first general public event, the Local Citizens Dialogue Session, will be conducted in-between the two National Stakeholder meetings and will be designed to allow for large group dialogue and deliberation. The three final Local Feedback Sessions will be conducted after the National Stakeholder Sessions (as brief evening sessions) to vet and solicit input regarding the proposals from the National Stakeholder Group and the Local Citizens Dialogue Session. Below is general logistical information regarding these sessions.

### **Local Citizens Dialogue Session—Atlanta, Georgia**

Saturday, August 27, 2005

### **Feedback Sessions**

An evening session in September/October in:

Massachusetts

Nebraska

Oregon

## **III. Roles**

### **STAKEHOLDER PARTICIPANTS**

Stakeholders committing to participate in the National Stakeholder Meetings will be expected to:

- ◆ Attend both two-day sessions in July and September;
- ◆ Adhere to the protocols adopted by the group;
- ◆ Engage in collaborative problem solving to address the range of interests brought to the table; and
- ◆ Work with their group/organization/constituency to understand their interests, to secure their on-going input, and to build support for final proposals.

### **CO-CHAIRS**

The National Stakeholder Sessions will be chaired by Ed Marcuse M.D., Associate Medical Director, Seattle Children's Hospital, ACIP and Roger Bernier, PhD, MPH, Senior Advisor for Scientific Strategy and Innovation National Immunization Program, CDC.

### **MEETING HOST**

The Institute of Medicine (IOM) will host the National Stakeholder Sessions. In this role, the IOM—in consultation with the stakeholders—will coordinate the technical consultants and other presenters to the Stakeholder Group.

## **Attachment B: Operating Protocols (continued)**

### **EXPERT CONSULTANTS**

Expert consultants asked to present and provide resource assistance to the Stakeholder Group will sit at the table with the stakeholder representatives and participate fully in plenary discussions. During small group discussions, expert consultants will be welcomed as observers and may be requested to provide resource advice to the stakeholders.

### **OBSERVERS**

Observers may be invited to attend the July and September National Stakeholder Meetings. Plenary and Small Group sessions will be open to observers. Observers will have clearly designated times for comments at the plenary and small group sessions.

### **STEERING COMMITTEE**

The Steering Committee is comprised of a representative cross-section stakeholder interests from the National Stakeholder Group. Their role is to provide on-going process and substantive guidance to support the deliberations of the National Stakeholder Group (see Attachment A).

### **FACILITATION AND PROCESS SUPPORT**

The Keystone Center will provide neutral facilitation and overall process support to the project. In consultation with stakeholders, The Keystone Center will assist with the convening, agenda development, facilitation, logistical support and coordination of and drafting of the meeting summaries and final report.

### **WORKING WITH THE PRESS**

The press is welcome to attend all plenary sessions of the National Stakeholder Group. The press will be notified/invited to the Atlanta Citizens Dialogue and the three Feedback Sessions. The Stakeholder Group will decide jointly if it desires to release a press statement about the group, the process, and/or outcomes and will jointly determine the method(s) and message. Individual stakeholders may talk with the press regarding their own perspectives/interests related to pandemic flu but will not characterize other stakeholders' comments or speak on behalf of the whole group.

### **FINANCIAL SPONSORS:**

The Richard Lounsbery Foundation  
Institute of Medicine  
The Keystone Center  
CDC National Immunization Program  
HHS National Vaccine Program Office  
Study Circles Resource Center

## **IV. Deliberating Guidelines and Approach to Developing Final Recommendations**

### **GENERAL APPROACH**

The National Stakeholder Group will approach their deliberations as collaborative problem-solvers seeking to produce proposals which satisfy all interests to the highest degree possible. The group will first work to jointly educate and build understanding regarding the participants' values and interests related to the issue while also developing a baseline understanding of essential scientific and technical information. Collaborative problem-solving is successful when parties agree that their major interests have been heard, taken into consideration and respected, the other participants have made every effort

## **Attachment B: Operating Protocols (continued)**

to address their interests in the final proposals, and the final proposals accurately characterize any outstanding differences.

### **SPECIFIC DELIBERATING GUIDELINES**

- A. It is presumed that comments made during the meetings are not for attribution and should not be assumed to be an official organizational position unless otherwise indicated.
- B. Participants will listen respectfully to and honor the dignity of all the members of the group.
- C. Participants agree to focus on the articulated purpose of the deliberations and respect the issues that are designated as “off the table.”
- D. Participants will not make use of the content from the deliberations in other areas unless authorized by the group.
- E. The group will strive for agreement among all members. The group will work to build proposals by identifying and exploring all parties’ interests and attempting to satisfy these interests to the greatest extent possible. When agreement is not possible, the group will work to accurately and respectfully understand and document the different perspectives on an issue.
- F. Effective deliberations hinge on the attendance and participation of the named representatives.

### **MEETING SUMMARIES**

The Keystone Center will prepare draft summaries of the meetings. Summaries will capture key issues, conclusions and agreed-upon next steps. Summaries will not attribute statements to individuals, except where specific commitments are made by individuals on behalf of his/her constituency. Participants will have the opportunity to correct the draft meeting summary prior to finalization.

### **FINAL REPORT**

The Keystone Center will work with participants to draft proposals and the final group report. All documents will be subject to group review and support prior to finalization. The final report will be forwarded to appropriate advisory committees (NVAC, ACIP) of the Department of Health and Human Services.

Input from the Atlanta Citizens Dialogue Sessions: A summary of the input from the Atlanta Citizens Dialogue Session will be presented to the September Session of the National Stakeholder Group for their consideration and will also be attached as an independent section of the final report.

Input from the Three Feedback Sessions: The input from the three Feedback Sessions will be summarized and forwarded to the members of the National Stakeholder Group for their consideration prior to finalizing their report (and will also be attached to final report as independent sections). The Keystone Center will coordinate—via emails and conference calls—with the National Stakeholder Group so that they may incorporate in the input from the Feedback Sessions into their final report.

## Attachment C: Values, Goals, and Population Handout

### **Regular Flu Season**

#### Example Values:

- ◆ Health as the greatest social good
- ◆ Autonomy
- ◆ Beneficence

#### Example Principle/Goal:

- ◆ Maintain the health of persons at highest risk of dying from influenza who voluntarily desire vaccine

#### Example Population/Sub-populations:

*Population: High Risk of mortality*

*Sub-populations:*

- ◆ Young children
- ◆ Elderly
- ◆ Pregnant women
- ◆ Underlying illness/injury

### **Pandemic Flu Event**

#### Illustrative values are:

- ◆ Health as the greatest social good
- ◆ Society's perceived needs are the greatest social good
- ◆ The marketplace is the wisest decision-maker
- ◆ Initiative and advocacy—first come first served should determine who obtains vaccine
- ◆ First do no harm—nonmaleficence
- ◆ Do good—beneficence
- ◆ Respect for autonomy—respect for and support for the personal choices that competent people decide to make as long as these choices do not negatively affect others
- ◆ Justice—demonstratively fair
- ◆ Subsidiary principle—decisions should be made as closely as possible to the citizens that will be affected
- ◆ Proportional response—any action must be proportional to the protection and relief needs of the people at risk
- ◆ Transparency of decision-making

#### Illustrative potential principles/goals for a national pandemic influenza vaccination program are:

- ◆ Assure maximum reduction of mortality from influenza that can be achieved with the available amount of vaccine
- ◆ Reduce mortality and morbidity of people at highest risk because of being elderly
- ◆ Reduce mortality and morbidity of people at highest risk because of being young
- ◆ Reduce mortality and morbidity of people at highest risk because of chronic disease/illness/injury
- ◆ Reduce risk of mortality or morbidity that may be in high risk because of the social and economic conditions (homeless, etc.)
- ◆ Override the personal preference of the individual if necessary to achieve the well being of the group
- ◆ Centralize control of vaccines in the public sector



## Attachment C: Values, Goals, and Population Handout (continued)

- ◆ Reduced mortality and morbidity of populations based on most cost effective program
- ◆ Avoid unjust discrimination against marginalized or vulnerable citizens
- ◆ Assure preferential vaccination of communities that are a high risk of morbidity because of remoteness and lack of access to health services
- ◆ Maintain health of individuals with financial ability to purchase vaccine
- ◆ Protect individuals who are able to access the vaccine first
- ◆ Provide net health benefits to people, keeping harm, if not fully available, at the lowest possible level
- ◆ Vaccinate those populations where vaccine will be most effective
- ◆ Minimize societal disruption
- ◆ Address historical social inequalities through vaccination prioritizations
- ◆ Maintain the health of persons able to implement pandemic response activities
- ◆ Maintain the health of persons who provide the greatest economic benefits to the community
- ◆ Maintain the health of mentally competent citizens
- ◆ Maintain the health of non-felony citizens
- ◆ Maintain the health of American citizens
- ◆ Maintain the health of persons that can support long-term recovery efforts
- ◆ Maintain the health of parents with dependent children and other care-givers
- ◆ Maintain the health of persons at highest risk of dying from influenza
- ◆ Maintain the health of persons most likely to transmit infection to persons at high risk of dying from influenza
- ◆ Maintain the health of persons most likely to pass on infection to anyone in the community
- ◆ Maintain the health of persons who provide vital social community services
- ◆ Maintain the health of persons able to provide quality health care

### Illustrative target groups and sub-populations

- ◆ Health care workers: nurses, doctors, hospital, outpatients
- ◆ Public safety workers: fire, EMS, corrections
- ◆ High risk outpatients: elderly, infants, chronically ill
- ◆ Long term critical care facility residents
- ◆ Essential service providers: pandemic health responders, health decision-makers, vaccine/antiviral manufacturers, government, utility, telecommunications, sanitation
- ◆ Business sector
- ◆ Parents
- ◆ Healthy adults
- ◆ Healthy children

## Attachment D: The Atlanta Journal-Constitution (AJC) Meeting Articles

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The Atlanta Journal-Constitution

August 26, 2005 Friday Home Edition

SECTION: News; Pg. 3C;

LENGTH: 595 words

HEADLINE: Atlantans to weigh in on flu

BYLINE: M.A.J. MCKENNA

### BODY:

About 100 metro Atlanta residents will gather Saturday to try something new: Instead of waiting for the government to tell them what to do in a health emergency, they plan to tell the government what they think.

The government seems to be listening.

The participants, recruited through public appeals and advertisements by a largely nonprofit coalition, will tackle a problem that worries government planners: how to distribute scarce vaccines and drugs if an influenza pandemic arrives in the United States.

The meeting, called the Public Engagement Pilot Project on Pandemic Influenza, is the creation of a researcher who has been at the Atlanta-based Centers for Disease Control and Prevention for almost 40 years.

"What to do about pandemic flu is not a purely scientific decision," said the scientist, Dr. Roger Bernier. "Public values will drive the decision as well. And we don't have good mechanisms for engaging citizens and scientists in dialogue so that a collective judgment can be arrived at that is a combination of science and values."

Bernier, who has worked on immunization for most of his professional life, realized the insufficiency of science several years ago when he was waiting to testify on Capitol Hill. Another witness, also waiting, dismissed Bernier's views out of hand because he represented the government.

"I was shocked, because I knew the quality of our research," Bernier recalled. "It was a wake-up call that doing more research would not solve the disagreement. It was an issue of trust."

He took a leave from his job to study the problem and developed a model for teaching citizens about scientific issues and eliciting their reactions in ways that --- he hopes --- do not talk down to them. The Atlanta meeting is the model's first test.

The participants, who were selected to represent a variety of ethnic and racial groups as well as a range of city and suburban neighborhoods, say they are looking forward to the experiment.

"I believe [a pandemic] could happen," said Sonya Jones, an Austell chef and entrepreneur. "I want to be educated about it, not just opinionated. And I am really intrigued to hear what other people think."

The Atlanta meeting is also the first step in a process that will take residents' fears and opinions about pandemic flu up the ladder to federal planners, a reverse of the usual pattern in which official decisions flow downhill. The project's supporters --- including the Institute of Medicine, a nonpartisan nonprofit group that advises Congress on health policy --- said they were drawn to it by that reversal. In most of the major health crises of the past few years --- from the anthrax attacks to the smallpox vaccination campaign to flu vaccine shortages --- health

## **Attachment D: The Atlanta Journal-Constitution (AJC) Meeting Articles (continued)**

authorities were criticized afterward for not giving the public enough information.

"We want to support more-informed dialogue in any way we can," said Dr. Kathleen Stratton, a senior program officer at the IOM who helped review the smallpox campaign.

The next step after Saturday will be a September review of the Atlanta residents' recommendations by health professionals meeting at the IOM in Washington. After that, the recommendations will be submitted for more public comment in town hall meetings in Maine, Nebraska and Oregon.

The final product will be delivered to the Department of Health and Human Services by October. The agency, which has worked for 12 years on the United States' response to pandemic flu, will include the recommendations in its final plan this fall.

### **AJC Post Meeting News Article**

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The Atlanta Journal-Constitution

August 28, 2005 Sunday Home Edition

SECTION: News; Pg. 9A;

LENGTH: 669 words

HEADLINE: Panel: Treat those most at risk of flu

BYLINE: M.A.J. MCKENNA

#### **BODY:**

The government's priorities in a worldwide influenza epidemic should be protecting those at most risk of dying from the disease --- infants, pregnant women, the elderly and those with chronic conditions --- as well as first responders and health care workers, a metro Atlanta citizens' panel recommended Saturday.

But they added a quick caveat: They do not trust the federal government to follow their recommendations, and they are not convinced that local health departments have the expertise to keep them safe.

The 99 city and suburban residents, recruited to contribute to federal plans for a flu pandemic, finished eight hours of deliberations Saturday with a call for rapid, honest communication from authorities to the public.

"They sound like they are listening. I hope that is the case," said Joy Johnson, a health care administrator who lives in Tucker. "They will need the support of citizens to make this work."

## Attachment D: The Atlanta Journal-Constitution (AJC) Meeting Articles (continued)

The meeting at downtown's Loudermilk Center for the Regional Community marked the first time that citizens have been asked to collaborate in the federal government's planning for a health emergency. It was hosted by the Public Engagement Pilot Project on Pandemic Influenza, a private endeavor started by a longtime researcher at the Centers for Disease Control and Prevention and supported by a coalition made up mostly of nonprofit groups. (The Atlanta Journal-Constitution contributed public service advertising.)

The meeting took place against a backdrop of rising concern over a possible pandemic, the technical description for a worldwide epidemic that arises in several places at once, moves quickly and leaves devastation in its wake. Past pandemics have killed at least 1 million people per episode; the worst on record, the "Spanish Influenza " of 1918, killed an estimated 50 million worldwide.

A strain of influenza that previously affected only birds, but since late 2003 has sickened at least 112 humans and killed 57 , has kicked long-dormant federal pandemic planning into high gear. The strain arose in Southeast Asia but has reached western Russia, prompting an emergency meeting of European health officials last week.

Health authorities have said that if avian flu changes genetically in ways that allow it to move more rapidly between humans, it will reach the United States before enough vaccine or preventive drugs can be stockpiled. That fear shaped the mission given to Saturday's participants: choosing which groups should be the first to receive scarce vaccine.

After several hours of lectures on flu basics and medical ethics, group members were asked to choose among five scenarios, from protecting those who would be at the highest risk of death to giving the vaccine to whoever asked for it first.

Each participant got three votes, which were recorded by stickers they placed on posters around the room. "Save those most at risk" got 133 votes, followed by "Limit the larger effects in society" with 104. "First come, first served" got four, the lowest number of votes

Despite an energetic buzz of conversation that forced participants to shout to be heard, some of them left the meeting skeptical that their efforts would make much difference.

"It worries me that, unless this is put into law, the people who benefit when the panic starts will be the powerful and the rich," said Michael Martin, a retired Gwinnett County banker.

The U.S. Department of Health and Human Services has said it will include the citizen recommendations in the final version of its pandemic plan, due to be released this fall by HHS Secretary Michael Leavitt. Other meetings are scheduled in Massachusetts, Nebraska and Oregon.

HHS and CDC researchers who observed Saturday's meeting said they valued the input.

"Most of the people here don't fall into the groups" they voted to give vaccine to, said Ben Schwartz of HHS' National Vaccine Program Office. "It's a pretty powerful indicator of the value of having the public join in the decision."

## **Attachment D: The Atlanta Journal-Constitution (AJC) Meeting Articles (continued)**

After several hours of lectures on flu basics and medical ethics, group members were asked to choose among five scenarios, from protecting those who would be at the highest risk of death to giving the vaccine to whoever asked for it first.

Each participant got three votes, which were recorded by stickers they placed on posters around the room. "Save those most at risk" got 133 votes, followed by "Limit the larger effects in society" with 104. "First come, first served" got four, the lowest number of votes

Despite an energetic buzz of conversation that forced participants to shout to be heard, some of them left the meeting skeptical that their efforts would make much difference.

"It worries me that, unless this is put into law, the people who benefit when the panic starts will be the powerful and the rich," said Michael Martin, a retired Gwinnett County banker.

The U.S. Department of Health and Human Services has said it will include the citizen recommendations in the final version of its pandemic plan, due to be released this fall by HHS Secretary Michael Leavitt. Other meetings are scheduled in Massachusetts, Nebraska and Oregon.

HHS and CDC researchers who observed Saturday's meeting said they valued the input.

"Most of the people here don't fall into the groups" they voted to give vaccine to, said Ben Schwartz of HHS' National Vaccine Program Office. "It's a pretty powerful indicator of the value of having the public join in the decision."

# Attachment E: ACIP and NVAC Recommended Pandemic Influenza Vaccine Priority Groups



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August 10, 2005

Cristina V. Beato, M.D.  
Acting Assistant Secretary for Health  
Director, National Vaccine Program  
Department of Health and Human Services  
200 Independence Avenue, SW, Rm. 716G  
Washington, DC 20201

**RE: NVAC – June 7-8, 2005 Meeting and  
NVAC/ACIP – July 19, 2005 Joint Committee Meeting**

Dear Dr. Beato:

As you know, last year's unexpected shortage of influenza vaccine and this year's urgent need to develop and implement a pandemic influenza plan have made for a remarkable twelve months for many branches of the Department of Health and Human Services. At your request, the National Vaccine Advisory Committee (NVAC) has been reviewing and advising on issues related to vaccine shortages and pandemic influenza. I am sorry you were unable to attend the recent regular meeting of the National Vaccine Advisory Committee (NVAC) in June and the special July 19<sup>th</sup> joint committee meeting of NVAC and the Advisory Committee of Immunization Practices (ACIP). This letter will update you on our progress.

Day 1 of our regular June meeting opened with a review by Jeanne Santoli of NIP of lessons learned from this past influenza season. Ray Strikas then reviewed current preparations for the season ahead and summarized the proceedings of this year's National Influenza Summit. These baseline presentations initiate an NVAC activity of annual evaluation of the influenza immunization program.

Alan Hinman then updated NVAC on activities of the Pandemic Influenza Working Group during meetings held on April 19-20 and June 15-16. The Working Group has been divided into two subgroups to facilitate more rapid progress. The Antiviral Subgroup has been working to develop a set of recommendations for stockpiling, distribution and use of antiviral drugs in the event of an influenza pandemic. The Vaccine Subgroup, a joint subgroup with the Advisory Committee on Immunization Practices, has been developing a set of recommendations addressing the use of influenza vaccine in the event of a pandemic.



## Attachment E: ACIP and NVAC Recommended Pandemic Influenza Vaccine Priority Groups

Additional presentations to NVAC included Jerome Klein's review of the proceedings and recommendations from the *2<sup>nd</sup> NVAC Workshop on Strengthening the Supply of Vaccine in the U.S.* and Sarah Landry's review of the Department's Pandemic Influenza Communications, Public Engagement, and Outreach activities. Dr. Klein noted that many of the supply workshop recommendations would become oversight tasks of the newly formed NVAC Subcommittee on Vaccine Development and Supply. Sarah Landry's presentation summarized the work being done by the PITFORCE Communications Group, an HHS cross-agency group to develop a pandemic influenza communications strategy, and by the Pandemic Flu Vaccination Priorities Public Engagement Pilot Project.

As you'll recall, we have changed the NVAC subcommittee structure to accommodate new challenges and changing priorities in vaccine and immunization policy. The new subcommittees (Vaccine Development and Supply, Communications and Public Engagement, and Vaccine Safety) had their first meetings on June 7<sup>th</sup>. They discussed their new charges and began setting new agendas. The Subcommittees have all continued their organizational conversations via conference call and are expected to report back to the NVAC in September.

The Subcommittee on Immunization Coverage discussed issues arising during a recent CDC and NVPO sponsored meeting, *Strengthening the Delivery of New Vaccines for Adolescents: A National Stakeholders' Meeting*. They determined the need for a Working Group on Adolescent Immunization to comprehensively address the complicated issues surrounding setting program goals, approaches to effectively and efficiently delivering vaccines, financing immunization; and enhancing demand.

The second day of the June NVAC meeting opened with summaries of the Subcommittee meetings. These were followed by a presentation about the NVPO's Unmet Needs Program, a summary of a report recently published by the Institute of Medicine entitled "Vaccine Safety Research, Data Access, and Public Trust, and a summary of the aforementioned meeting on adolescent immunization. In preparation for the next fiscal year's unmet needs funding, Ben Schwartz provided an overview of the previous two year's priorities and funding and requested volunteers from the Committee to participate in the determination of priority categories and the review of proposals. Dr. Debra Lappin, a member of the IOM Committee on the Review of NIP's Research

Procedures and Data Sharing Program, gave an overview of the committee's findings and recommendations, published earlier this year in which they recommend the NIP develop, with the input of key stakeholders, an annual Vaccine Safety Datalink research plan and that the NVAC develop a subcommittee to review the NIP's annual plan.

Last, but not least, the June NVAC meeting concluded with valuable agency and committee updates presented by: NIP/ACIP (Dr. Larry Pickering - CDC), ACCV/DVIC (Dr. Geoff Evans - HRSA), FDA/VRBPAC (Dr. Norman Baylor - FDA/CBER), NVPO (Dr. Bruce Gellin), and NIH/NIAID (Dr. George Curlin).

On July 19<sup>th</sup>, the ACIP and the NVAC held concurrent committee meetings to make recommendations regarding prioritization for the use of vaccines in the event of a pandemic influenza. The NVAC unanimously voted to recommend the priority structure depicted in the following table, with the understanding that, as a pandemic event unfolds, it may be determined that an alternate structure may be more effective. The ACIP voted independently of NVAC for the same prioritization structure. The ACIP's recommendations will be submitted to the Director of the Centers for Disease Control and Prevention.

## Attachment E: ACIP and NVAC Recommended Pandemic Influenza Vaccine Priority Groups

### NVAC Recommended Pandemic Influenza Vaccine Priority Groups

<u>Element and Tier</u>	<u>Personnel (1,000's)</u>	<u>Cumulative total (1,000's)</u>
<b>1A.</b> Health care workers involved in direct patient contact & essential support	9,000	9,000
Vaccine and antivirals manufacturing personnel	40	9,040
<b>1B.</b> Highest risk group	25,840	34,880
<b>1C.</b> Household contacts children <6 months, the severely immunocompromised, and pregnant women	10,700	45,580
<b>1D.</b> Key government leaders & critical public health pandemic responders	151	45,731
<hr/>		
<b>2A.</b> Rest of high risk	59,100	104,831
<b>2B.</b> Most CI and other PH emergency responders	8,500	113,331
<hr/>		
<b>3.</b> Other key government health decision makers & mortuary services	500	113,831
<hr/>		
<b>4.</b> Healthy 2-64 years not in other groups	179,260	293,091

The ACIP having adjourned its meeting, the NVAC continued in session to develop recommendations on the purchase of vaccines during a pandemic. After careful review of the options, the Committee unanimously recommended the Federal purchase of all vaccine during a pandemic. The Committee also recommended that the distribution of vaccine occur through systems established by state, local, and Federal agencies in advance of a pandemic event.

Again, after review of options and with the understanding that these recommendations may need to be revisited during a pandemic event due to unanticipated responses to both vaccine and antivirals and developing epidemiology of the particular influenza virus that may cause a pandemic event, the Committee voted to recommend the following antiviral drug use and prioritization strategies:

1. Sufficient antiviral drugs should be maintained in stockpiles to support a robust pandemic response because of the key role that antiviral drugs can play in reducing health impacts of an influenza pandemic, particularly early in the pandemic when vaccines may be unavailable. Stockpiling is essential because the available supply of neuraminidase inhibitors in the pipeline and ongoing production will not contribute substantial quantities of drug to an antiviral response.
  - a. A stockpile that includes about 133 million treatment courses would provide sufficient antiviral drugs to treat all who are infected and support prophylaxis of health care workers and the highest risk population groups (see priority groups and strategies, below). About 40 million courses is considered to be the minimum stockpile size that would support the most critical pandemic response needs.

## Attachment E: ACIP and NVAC Recommended Pandemic Influenza Vaccine Priority Groups

- b. Within this wide range, stockpiles that exceed the minimum would be advantageous for several reasons:
- i. The primary pandemic response goal of reducing severe morbidity and mortality would be best achieved with sufficient antiviral drugs to treat all who are infected and to provide prophylaxis to several key occupational and patient groups;
  - ii. Greatest equity and public acceptance would be achieved with sufficient antiviral drugs to treat all those who are infected;
  - iii. In a more severe pandemic, prophylaxis beyond what is projected may be required to avoid absenteeism among health care workers and other pandemic responders due to fear of becoming infected;
  - iv. Groups at greatest risk for severe morbidity and mortality have differed among past pandemics and may be larger than predicted;
  - v. Optimal treatment may require a higher dose or longer course of therapy than for annual influenza based on results of an animal model of H5N1 infection, so that the actual number of courses available would be less than projected; and
  - vi. Some antiviral drugs may be used for treatment and for prophylaxis of contacts associated with the first cases of pandemic influenza introduced into the U.S. Depending on the intervention strategy, substantial quantities of antiviral drugs could be used attempting to slow the spread of disease.
2. Oseltamivir should be the primary antiviral drug stockpiled. Zanamivir also should be included because it is effective against many oseltamivir resistant strains; supporting ongoing production of both agents increases protection against supply disruptions; and, given the limited availability of oseltamivir before the end of 2006, purchase of zanamivir could accelerate preparedness. Because zanamivir is delivered by inhalation and achieves lower systemic concentrations, its use may be preferable during pregnancy. Risks and benefits should be considered. Adamantanes, beyond the 5 million courses of rimantadine currently in the SNS, should not be stockpiled due to the likelihood of antiviral resistance.
3. Proposed target groups, in priority order, and drug use strategies are shown in the Table. The number of groups targeted would depend on the size of the available stockpile. Although small additional quantities of oseltamivir may be obtained from the supply chain at the time of a pandemic, this quantity would be limited making it unlikely that additional groups could be targeted. Additional information on target group definitions and the rationale for their inclusion is included in the Annex.

**Attachment E: ACIP and NVAC Recommended Pandemic Influenza Vaccine Priority Groups**

Target Group	Approximate population (in millions)	Strategy	# Courses (in millions)	
			For target group	Cumulative
Patients admitted to hospital*	10.0	T	8.0	8.0
HCWs and EMS providers with direct patient contact	9.2	T	2.4	10.4
Highest risk outpatients	2.5	T	0.7	11.1
Pandemic health responders, public safety & key government decision makers	3.3	T	0.9	12.0
Increased risk outpatients	85.5	T	22.4	34.4
Outbreak response**	NA	PEP	2.0	36.4
HCWs in ER, ICU, EMS, and dialysis settings	1.2	P	4.8	41.2
Pandemic societal responders & other HCWs	10.2	T	2.7	43.9
Other outpatients	180	T	47.3	91.2
Highest risk outpatients	2.5	P	10.0	101.2
Other HCWs with direct patient contact	8.0	P	32.0	133.2

Notes on priority group recommendations:

\*No studies have assessed the impacts of antiviral treatment for patients admitted to hospital where complications already may be present and the interval from illness onset to therapy is likely to be longer. Additional data should be collected from annual influenza and early in a pandemic to determine whether this represents an effective use of resources when available antiviral drug supply is limited.

\*\*Outbreak response includes post-exposure prophylaxis in nursing homes and other closed settings where risk of transmission and severe outcomes of infection are high.

4. Use of antiviral drugs from the U.S. stockpile is recommended to support an international effort to contain an outbreak caused by a novel influenza strain, potentially preventing a pandemic, if the following conditions are met: 1) International guidelines and protocols are developed and accepted describing the intervention strategy and when it would be implemented; 2) Field exercises in countries where an initial outbreak may occur suggest an ability to effectively implement containment; and 3) Other industrialized countries with antiviral stockpiles also contribute to this effort.

Attachment E: ACIP and NVAC Recommended Pandemic Influenza Vaccine Priority Groups

5. Critical research should be conducted to support development and implementation of optimal recommendations for pandemic influenza antiviral drug use. Studies that should be supported include:
  - a. Impact of treatment at hospital admission on morbidity outcomes, including length of hospital stay.
  - b. Optimal treatment dose and schedule in a ferret model with H5N1 and other influenza strains with pandemic potential.
  - c. Sensitivity of rapid diagnostic tests for H5N1 and other influenza strains with pandemic potential using nasal and throat swab specimens.
  - d. Safety and pharmacokinetics of oseltamivir among infants <1 year old.
  - e. Investigation of the impact of other drugs (antiviral and other classes such as statins) on influenza.
6. Additional work with public and private sector groups should be done to further hone definitions of target groups and their estimated population sizes, and to provide further guidance on antiviral drug distribution and dispensing.

As you can see, the past two months have posed particularly significant challenges to NVAC, the NVPO and other USPHS support staff. Thanks to hard work by all, it has been possible to gather and digest the information necessary to offer advice in a timely fashion in this area of national import.

Feel free to contact me with any questions or concerns you may have in regard to our last NVAC meetings. The next NVAC meeting is scheduled for September 27-28, 2005. We hope you will be able to join us.

Sincerely yours,



CHARLES M. HELMS, M.D., Ph.D.  
*Chairman, National Vaccine Advisory Committee*

*Professor of Medicine  
Roy J. and Lucille A. Carver College of Medicine  
University of Iowa*

*Chief of Staff  
University of Iowa Hospital and Clinics*

CH/ee

cc: Bruce Gellin, M.D., M.P.H.  
NVAC members

# Attachment F: Monica Schoch-Spana's Presentation on Myths

## Public Responses to Extreme Events – Top 5 Disaster Myths

Monica Schoch-Spana  
Center for Biosecurity of the  
University of Pittsburgh Medical Center

Remarks – September 7, 2005  
Public Engagement: Pandemic Influenza Vaccine Priorities  
Washington, DC

### INTRODUCTION

- Rudyard Kipling published a collection of fanciful stories entitled *Just So Stories*, describing how the world came to be; for example, “how the elephant got his trunk,” “how the camel got his hump.”
- “Just So Stories” are often the basis for public policy decisions in disaster preparedness, response and recovery. These kinds of tales typically are not about “how the world came to be,” but about “how things fall apart.”
- With a 10 minute talk, I thought listing the top myths about mass responses to disaster would make the best use of our time and set the stage for discussion. My plan is to relate the key disaster myths, present the facts that call them into question, and illustrate them through specific case studies.
- I am exploiting the work of other scholars, namely those in the history of medicine and the sociology of hazards and disasters. Special thanks to:

John Barry  
Gregory Button  
Lee Clarke  
Alfred Crosby  
Russell Dynes  
Henry Fischer III  
Tom Glass  
Eric Klinenberg  
Judith Walzer Leavitt  
Denis Mileti  
Walter Peacock  
E.L. Quarantelli  
Kathleen Tierney  
Many others...



## Attachment F: Monica Schock-Spana's Presentation on Myths

**MYTH #1: Disasters are equal opportunity events; they happen in random and quirky, but essentially democratic ways.<sup>1</sup> Hurricanes, outbreaks, heat waves, earthquakes, and chemical spills kill indiscriminately. They do not care “who” the victim is.**

FACT: People are more or less vulnerable to the effects of disasters; social class, ethnicity and race, gender, and social connectedness are factors that often determine the extent of harm. These traits also play an important role in resilience to, and speedier recovery from crisis.

### **1995 Chicago Heat Wave Singled Out the Poor, the Elderly, and the Isolated<sup>2</sup>**

- Between July 13 and July 20, Chicago experienced a record-breaking heat wave that claimed more than 700 lives.
- Most victims were low-income elderly people who lived alone, were isolated from friends and family, and were left abandoned for days before being discovered. 73% of the victims were age 65 or older, a majority of whom were African-American.
- Deaths were not caused by extreme temperatures alone; existing social conditions common to urban areas compounded the effects of the heat. A substantial number of seniors live alone in unsafe, decrepit, low-income housing in neighborhoods that have been abandoned by businesses, service providers, and many residents.
- These conditions create a culture of isolation and fear that discourages seniors from trusting neighbors or even leaving their homes. Minority seniors were especially vulnerable to the heat wave because they are largely homebound, with no one checking in on them and nowhere to turn for help.

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<sup>1</sup>Walter Peacock. *Consequences of Disaster Myths*, 30<sup>th</sup> Annual Hazards Research and Applications Workshop, Boulder, CO, July 12, 2005.

<sup>2</sup>Eric Klinenberg. *Heat Wave: A Social Autopsy of Disaster in Chicago*. Chicago, IL: University of Chicago Press; 2002.

**MYTH #2: Whether people comply with evacuation plans, isolation and quarantine, or other public health and safety orders is strictly a matter of “personal choice.”**

FACT: The problem of “non-compliance” has less to do with handling willful, obstinate or ignorant individuals than with rectifying life circumstances that interfere with an ability to act according to authorities’ reasonable requests.

- Homelessness, drug addiction, and mental illness, for instance, impeded many disadvantaged tuberculosis patients in the 1990s from fully completing their rigorous, medical treatment schedule, thus posing the risk of developing drug resistant strains of TB during the larger HIV/AIDS epidemic.<sup>3</sup>
- University of New Orleans researchers who surveyed the city's residents about their personal hurricane evacuation plans in 2004 estimated that at least 100,000 New Orleans residents had no means to evacuate: no car, not enough money for airfare or a bus ticket, no friends or family to help them leave town.<sup>4</sup>
- During the 1918 Spanish Flu pandemic, some Baltimore city residents berated health officials for curtailing retail business hours to control influenza’s spread: hourly workers lost wages including income to pay for extra heating fuel, an item they considered more critical to protecting their families.<sup>5</sup>

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<sup>3</sup>Ron Bayer and Laurence Dupuis. Tuberculosis, public health, and civil liberties, *Annual Review of Public Health* 1995;16:307–26.

<sup>4</sup>Cox News Service. Many New Orleans residents had no evacuation plan. September 2, 2005.

<sup>5</sup>Monica Schock-Spana. Psychosocial consequences of a catastrophic outbreak of disease: Lessons from the 1918 pandemic influenza. In: Robert Ursano, Ann Norwood, and Carol Fullerton, eds. *Bioterrorism: Psychological and Public Health Interventions*. New York: Cambridge University Press; 2004, pp. 38-55.

## Attachment F: Monica Schock-Spana's Presentation on Myths

### **MYTH #3: When life and limb are threatened on a mass scale, people panic. They revert to their savage nature, and social norms readily break down.**

FACT: According to extensive social research, people rarely fall apart and put themselves first.<sup>6,7,8,9</sup> This finding contradicts what people tend to say on surveys that ask them how they *think* they will behave when disaster hits. In reality, people may feel fearful, anxious and capable of doing just about anything to protect their loved ones. They may be irritable with politicians and safety professionals and ignore their advice when it is irrelevant to their situation. But, contrary to the scary stories authorities tell each other, panic is the exception. Creative coping is the norm.

- Ordinary people emerge as innovative problem-solvers who are responsive to the needs of others around them. This pro-social response has been documented by researchers over several decades in countless disasters, and has been bolstered by reports of the reasoned and altruistic responses of those directly affected in the 9/11 attacks and the recent London bombings. People react in disaster the same way they live: as parents, as co-workers, neighbors, members of faith communities.
- Regular people are not merely disaster victims who must rely on trained responders for protection. Studies show that the majority of people rescued are saved by non-professionals who happen to be in the immediate vicinity. 49 of 50 people saved from the rubble of the 1989 Loma Prieta earthquake in California were rescued by a group of 8 Mexican construction workers who have long since been forgotten in the larger U.S. cultural narrative of the heroic efforts by trained, search-and-rescue professionals.

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<sup>6</sup>Lee Clarke. Panic: Myth or reality? *Contexts* 2002; Fall:21–6.

<sup>7</sup>E.L. Quarantelli. The sociology of panic. In: Smelser N, Baltes PB, eds. *International encyclopedia of the social and behavioral sciences*. New York: Pergamon Press; 2001:11020–30.

<sup>8</sup>Henry W. Fischer. *Response to disaster: Fact versus fiction and its perpetuation*. Lanham, MD: University Press of America; 1994.

<sup>9</sup>Russell R. Dynes and Kathleen J. Tierney, eds. *Disasters, collective behavior and social organization*. Newark, DE: University of Delaware Press; 1994.

<sup>10</sup>Tom Glass. Workshop remarks, *Citizens' Information Needs in Responding to Disaster*. Computer Science and Telecommunications Board of the NAS/National Research Council, Washington, DC, July 19, 2005.

### **MYTH #4: Command-and-control is the most effective management approach to an “emergency.” Centralized, insular decision-making and authority structures among trained professionals guarantee the least harm to people and property. Ordinary civilians and everyday institutions are inadequate to deal with crises.**

FACT: Shared problem-solving across sectors and social groups, rather than imposing authority from outside, is a more effective tool for handling extreme and/or unanticipated events.<sup>11</sup>

The very different outcomes of two U.S. smallpox outbreaks—one in Milwaukee in 1894 and the other in New York in 1947—suggest that disease controls that compromise democratic ideals of self-determination and equality of persons can inadvertently spread an epidemic further.<sup>12</sup>

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<sup>11</sup>Russell R. Dynes. Community emergency planning: false assumptions and inappropriate analogies. *International Journal of Mass Emergencies and Disasters* 1994;12(2):141-158.

<sup>12</sup>Judith W. Leavitt. Public resistance or cooperation? A tale of smallpox in two cities. *Biosecurity and Bioterrorism*. 2003;1(3):185-92.

#### CASE STUDY – SMALLPOX IN MILWAUKEE 1894

- Facing a citywide outbreak, Milwaukee health authorities forcibly removed infected individuals to isolation hospitals considered substandard, selectively using this technique among impoverished immigrants.
- Wealthier smallpox patients were placed under quarantine and encouraged to care for their afflicted loved ones in the comfort of their own homes.
- Perceived to be discriminatory and authoritarian, these public health measures caused month-long riots and ultimately abetted the spread of smallpox.
- Outbreak Impact: 1,079 cases, 244 deaths

## Attachment F: Monica Schock-Spana's Presentation on Myths

### CASE STUDY – SMALLPOX IN NYC 1947

- NYC officials effectively quelled outbreak by implementing a voluntary mass vaccination campaign that was universally applied, carrying out an elaborate public relations campaign, and involving grassroots organizations.
- Health officials were legally authorized to vaccinate people or move patients to hospitals forcibly, but coercive measures were unnecessary in the context of a community-wide and evenly applied containment campaign.
- 6,350,000 people were vaccinated in 4 weeks (5 million along in the first 2 weeks)
- Outbreak impact: 12 cases, 2 deaths

**MYTH #5: Acts of God and Nature are pre-ordained. There is no real way to thwart their ultimate outcome. The same goes for Bureaucratic Red-Tape, another so-called immutable force.**

FACT: Modern disasters are complex, dynamic events. They involve the interaction of multiple systems – society, the built environment, and the natural world. Thoughtful tinkering to align these systems can help reduce hazards, though never remove them entirely.<sup>13</sup>

- Hurricane and earthquake hazards have lessened over time in the U.S. as building codes have improved the resistance of buildings to damage, the prediction of weather and geologic events has become more precise, and public warning systems and evacuation plans have been put in place.
  - According to Storm Data, for the 1975 to 1994 period hurricanes were the second most costly natural hazard in terms of property losses and the third most injurious. Because of advance warnings and emergency preparedness, hurricanes are only the seventh-leading cause of death due to natural disasters.<sup>14</sup>
  - Deaths and injuries attributable to hurricanes and tropical storms appeared to decline or, at a minimum, remain steady for the period 1975 to 1995.
- In 1995, *Washington Monthly* chronicled the successful reform of FEMA, from what many considered to be the “worst” federal agency to the best.<sup>15</sup>
  - Transformation took place in the aftermath of Hurricane Andrew, August 24, 1992. The storm leveled a 50-mile path across Southern Florida, leaving almost 200,000 people homeless and 1.3 million without electricity. Food, clean water, shelter, and medical assistance were in short supply. FEMA was absent for the first 3 days, and once on the scene, it poorly managed the relief effort.
  - FEMA was hampered by its lack of experienced managers and by its reactive posture to disaster, seeing itself as a “last responder” whose primary role was to distribute loans for rebuilding after a disaster. FEMA had 10 times the proportion of political appointees of most other government agencies.
  - Organizational restructuring, mission re-evaluation, energetic oversight, and strong leadership turned the agency around...

<sup>13</sup>Dennis S. Mileti. *Disasters by design: a reassessment of natural hazards in the United States*. Washington, DC: John Henry Press, 1999.

<sup>14</sup>Ibid, p. 76, 78.

<sup>15</sup>Daniel Franklin. The FEMA phoenix: reform of the Federal Emergency Management Agency. *Washington Monthly* July/August 1995. Available at <http://www.washingtonmonthly.com/features/2005/0509.franklin.html>; accessed September 2, 2005.

## Attachment F: Monica Schock-Spana's Presentation on Myths

### CONCLUSIONS

Emergency planning assumptions backed by empirical research, not hunches or common-sense notions:

- Disasters have the most profound effects for the already vulnerable members of society. Disasters are not equal opportunity events.
- Life circumstances – such as economic means, educational levels, and states of social isolation or connection – are more frequently the contributors to people's failure to heed reasonable official instructions, NOT individual traits of obstinacy or willfulness.
- In conditions of grave danger, creative coping is the norm and panic the exception.
- Shared problem-solving models, rather than ones of command-and-control, provide opportunities for flexibility and innovation, and a higher likelihood of enhanced preparedness, response, and recovery.
- The outcomes of a disaster – whether so-called natural, technological or terrorist-driven – are not set in stone or predetermined. That said, interventions must take into consideration complex interactions among citizens and government, as well as physical, natural, and built environments.

## Attachment G: Goals/Advantages/ Disadvantages

### Starting Point List of Potential Goals for a National Pandemic Influenza Vaccination Program

#### Assumptions/Scenario:

- ◆ **Severity:** Moderately severe pandemic in the U.S. with half a million deaths and two million hospitalizations.
- ◆ **Attack rate:** All age groups are attacked equally by the virus.
- ◆ **Death & Hospitalization rates:** Death and hospitalization rates will be highest in infants under 1 and persons 65 and older, but could vary from these past patterns.
- ◆ **Who Guides Choices:** Guidance about who first to vaccinate comes from the federal government.
- ◆ **Supply Control:** Government buys and distributes all the vaccine.
- ◆ **Payment:** Who pays for the vaccine is undecided.
- ◆ **Drugs:** Antivirals are adequate only to treat the very sick but not for prevention.
- ◆ **Supply Availability:** Only 3 million persons per month vaccinated—very limited supplies of vaccine become available in the early days of the pandemic—perhaps only enough to vaccinate 3 million persons per month starting 3-6 months after the pandemic begins or up to 18-27 million persons in first year of the pandemic.
- ◆ **Supply Distribution:** Vaccination is distributed at the same time to all states across the country based on population size.
- ◆ **Supply Use:** No tiering—because of limited supplies, assume the most vital members of each group must be vaccinated in sequence one after another in priority order before moving on to the next group. Only if supplies are adequate to cover more than one group would we vaccinate two or more groups simultaneously (tiering, e.g. vital vaccine makers, vital health care workers, vital policemen in first tier).
- ◆ **Supply Use:** Assume that all the vaccine is given fairly within a category of vital persons (e.g., senior surgeon not before young resident or vital food handler).
- ◆ **Who Qualifies:** Only the most vital included—assume only most vital members of a category (e.g., front line workers in public safety such as policemen on patrol and their support staff, such as dispatchers) would be included in a recommendation to vaccinate the category.
- ◆ **Who Qualifies:** Vaccine is used to protect the persons it is given to or their close contacts and not primarily to decrease transmission in the general population.
- ◆ **Who Qualifies:** Vaccine is used only in persons for whom it works well.
- ◆ **Who Qualifies:** Vaccine is not used in nursing home residents.

#### Charge to the Group:

Four core tasks and activities for the citizen and stakeholder groups:

1. Add or subtract from the starting point list of goals.
2. Clarify and deepen understanding of the goals and their consequences/tradeoffs.
3. Rank the goals in the order of their importance.
4. Seek the maximum agreement possible on the ranked list.

**Goals: Categorized by Vaccine Distribution Method, Benefits to Individuals, and Benefits to the Larger Society**

The most important overall goal of the Program will be to vaccinate everyone who wishes to be vaccinated. However, we cannot expect to achieve this in the early days of a pandemic when there will not be enough vaccine for everyone. Thus, the early goals of the program must be different from the overall goal and could include the following:

BY DISTRIBUTION METHODS

**#1. Give everyone an equal chance to be protected.**

**A. Lottery**

**B. First come, first served policy**

**1A. Lottery**

**Values:** If chosen, this goal would uphold fairness as the most important value to us.

**Other Values Upheld...**

**Groups:** The goal implies that anyone could be selected regardless of age, occupation, status, citizenship, income, or health condition. The goal could be implemented through a lottery with all residents in the U.S. given a chance.

**Consequences:** Some persons who win the lottery might not want to be vaccinated or might wish to donate their vaccine to another person.

**Other Consequences Anticipated...**

**#1B. First come, first served policy**

**Values:** If chosen, this goal upholds the values of fairness and personal autonomy and responsibility.

**Other Values Upheld...**

**Groups:** This goal implies that the persons vaccinated would be those who are aware of the need for vaccination and are most willing to take the initiative to get themselves vaccinated.

**Other Groups Implied...**

**Consequences:** This choice might create a rush on the vaccine before limited supplies run out.

**Other Consequences Anticipated...**

BY BENEFITS TO INDIVIDUALS

**#2. Protect persons with the most life ahead of them**

**Values:** If chosen, this goal upholds the duty we feel to protect children from harm. It also upholds the concept of “fair endings”, i.e., that everyone has the right to a full measure of life expectancy.

**Other Values Upheld...**

**Groups:** This goal implies that young persons below a certain age would be vaccinated preferentially.

**Consequences:** Children might live but be left without parents to take care of them.

**Other Consequences Anticipated...**



## Attachment G: Goals/Advantages/ Disadvantages

### #3. Seek to protect those of any age or health condition most or more likely to die from a new influenza strain

**Values:** If chosen, this goal would uphold the value of every human life no matter the age or condition of that life.

#### **Other Values Upheld...**

**Groups:** The goal implies that we would wait until the pandemic strikes, determine who is at greatest risk of dying from influenza at that time, and then vaccinate first those persons, young or old, frail or healthy, at greatest risk of dying. If saving lives of any kind is paramount, health care workers who treat sick patients might also qualify to be vaccinated in the first priority group. Also, the contacts of persons who might expose those at greatest risk of dying (e.g. parents of infants <1) might be included.

**Consequences:** We could not know prior to the pandemic who to target for vaccination. Also, some persons already relatively near death from other causes besides influenza would receive influenza vaccine.

#### **Other Consequences Anticipated...**

BY BENEFITS TO THE LARGER SOCIETY

### #4. Assure public safety

**Values:** This goal recognizes the importance of personal safety without which other things cannot take place.

#### **Other Values Upheld...**

**Groups:** The goal implies that policemen and national guardsmen and other persons like them would receive vaccine first.

#### **Other Groups Implied...**

**Consequences:** Choosing this goal assumes that citizens will NOT be law-abiding during a crisis. This assessment could be wrong.

#### **Other Consequences Anticipated...**

### #5. Maintain emergency and/or life saving services

**Values:** If chosen, this goal recognizes that saving lives is paramount above everything else.

#### **Other Values Upheld...**

**Groups:** This goal implies that those who provide services that are directly life saving would be protected first, such as health care workers, public health responders, emergency response personnel, firemen and other persons like them with direct patient contact or front line duties who contribute directly to saving lives.

#### **Other Groups Implied...**

**Consequences:** Determining exactly which sub-groups among these larger groups are most in need of vaccination may prove difficult, but front-line workers would presumably be eligible.

#### **Other Consequences Anticipated...**

## Attachment G: Goals/Advantages/ Disadvantages

### #6. Protect society's key government leaders and decision-makers

**Values:** Making this goal primary recognizes that society cannot function without the persons in charge of making decisions and responsible for public welfare.

**Other Values Upheld...**

**Groups:** This goal implies that the leaders with the most responsibility would be the most irreplaceable and the ones to be vaccinated first, starting with the President and including other hard to replace government leaders at the federal, state, and local level.

**Other Groups Implied...**

**Consequences:** Leaders choosing to have themselves included among the vaccinated could be viewed as self-serving unless the choice was made by citizens or others without apparent conflicts of interest.

**Other Consequences Anticipated...**

### #7. Protect those providing the most critical services which keep society running

**Values:** This goal upholds the importance of the essential support services that keep society functioning and which contribute indirectly to saving lives.

**Other Values Upheld...**

**Groups:** If selected as primary, this goal implies that utility workers, food distributors, embalmers/funeral directors and others like them would be vaccinated first.

**Other Groups Implied...**

**Consequences:** Determining who qualifies will be difficult as the group is potentially very large and many types of services contribute indirectly to sustaining life. Distinctions might be difficult to make. Also, not all members of a category would need to be vaccinated, but only key persons within those essential categories.

**Other Consequences Anticipated...**

### #8. Provide some vaccine to other countries even if it is at the expense of vaccinating some persons in the U.S.

**Values:** This goal upholds the importance of international cooperation and humanitarian activities for those less fortunate than the U.S. in obtaining even limited supplies of vaccine.

**Other Values Upheld...**

**Groups:** This goal implies that citizens of other countries would receive some of the U.S. vaccine supply.

**Consequences:** An already short supply of vaccine for persons living in the U.S. would be cut even further by donations to other countries with no vaccine at all or even less vaccine than the U.S..

**Other Consequences Anticipated...**

### #9. Protect those who provide homeland security and those who defend us against military threats abroad

**Values:** This goal upholds the importance of defending our country against military and other threats.

**Other Values Upheld...**

**Groups:** If selected as paramount, this goal implies that soldiers and other key homeland security

## Attachment G: Goals/Advantages/ Disadvantages

personnel would be vaccinated wherever they are deployed.

### **Other Groups Implied...**

**Consequences:** Persons in other countries may experience more or less risk than persons in the U.S. Protecting those responsible for our national defense abroad may have no impact on the spread of the pandemic in the U.S.

### **Other Consequences Anticipated...**

## **#10. Assure vaccine production**

**Values:** This goal recognizes that necessity of protecting those associated with the vaccine.

### **Other Values Upheld...**

**Groups:** This goal implies that the makers of vaccine and vaccinators would be first in line to be vaccinated.

### **Other Groups Implied...**

**Consequences:** Many types of persons are involved in the entire chain of vaccine development, production, distribution, and administration. Differentiating the key workers might prove difficult.

### **Other Consequences Anticipated...**

## **Starting Point List of Goals At-A-Glance**

BY DISTRIBUTION METHODS

### **#1. Give everyone an equal chance to be protected**

**A. Lottery**

**B. First come, first served policy**

BY BENEFITS TO INDIVIDUALS

### **#2. Protect persons with the most life ahead of them**

### **#3. Seek to protect those of any age or health condition most or more likely to die from a new influenza strain**

BY BENEFITS TO THE LARGER SOCIETY

### **#4. Assure public safety**

### **#5. Maintain emergency and/or life saving services**

### **#6. Protect society's key government leaders and decision-makers**

### **#7. Protect those providing the most critical services which keep society running**

### **#8. Provide some vaccine to other countries even if it is at the expense of vaccinating some persons in the U.S.**

### **#9. Protect those who provide homeland security and those who defend us against military threats abroad**

### **#10. Assure vaccine production**

# Attachment H: Goals–Summary of Group’s Discussion

## National Stakeholders Meeting *Summary of Group’s Goal Discussion* September 8, 2005

### **Goal 1: Lottery**

- ◆ It looks and sounds fair but after examining the real implications of a lottery there are serious concerns.
- ◆ Citizens might have an equal chance to be vaccinated but it would not translate into an equal chance of receiving protection from the vaccine.
- ◆ It would provide real opportunities for manipulation.
- ◆ Two benefits are the perception of fairness and providing a fast method to get citizens vaccinated.
- ◆ It could create a black market for vaccines.
- ◆ There are major logistical challenges.

### **Goal 2: Protect persons with the most life ahead of them**

- ◆ It would be very hard to identify criteria for the assignment of vaccine.
- ◆ We do have a cultural tradition to protect our young—and to respect the natural order not to bury young first.
- ◆ How do you assess life expectancy?
- ◆ This goal ignores the need to keep society functioning during the crises, and how societal chaos will have worse implications on the young.
- ◆ We need to clearly communicate WHY groups were not chosen to be vaccinated as a high priority.

### **Goal 3: Seek to protect those of any age or health condition most or more likely to die from a new influenza strain**

- ◆ This resonates with our culture and our health care providers.
- ◆ This decision needs to be based on the epidemiology of the event. Is this a wise use of resources to start with those who are already weak in health or who may be more vulnerable to other diseases?

### **Goal 4: Assure public safety**

- ◆ This is a crucial consideration but will be a challenge to determine what functions this means.
- ◆ We must vaccinate health care workers, if you do not, what incentive is there for them to show up for work?
- ◆ We need to protect those whose jobs are on the frontline.
- ◆ We need a strategy to guarantee that public safety workers will continue to work after they are vaccinated.
- ◆ We need to link with the work done by the Department of Homeland Security who are already addressing the specifics of this question.

## Attachment H: Goals–Summary of Group’s Discussion

### ***Goal 5: Maintain emergency and/or life saving services***

- ◆ We believe that conceptually this is important but we need to carefully prioritize the key groups within this category.
- ◆ If healthcare workers are vaccinated they must commit to serve.
- ◆ Do families of healthcare workers need to be vaccinated to guarantee that healthcare workers will come to work?
- ◆ If it is a feasible goal, we also need to consider reducing transmission.
- ◆ Which services are essential?

### **Goal 6: Protect society’s key government leaders and decision-makers**

- ◆ It may be important to identify key functions that are essential to keeping society going, but not vaccinate all government officials.
- ◆ How wide is the span? How far down the list?
- ◆ We do think that protecting government leaders will be a component of keeping society functioning.
- ◆ Public trust will be an issue. Will the public view these people as important decision-makers or just people who are out for themselves? It is the function that matters, not the person.

### **Goal 7: Protect those providing the most critical services which keep society running**

- ◆ After the Katrina hurricane, this is clearly an important goal.
- ◆ This may cause a backlash from those not deemed essential. This in some ways goes against the American value that all persons are equal.
- ◆ If vaccinated, the individual must perform their role/contribution to society.
- ◆ What would be the impact if some workers choose to stay home with family? Might there be situations where this is also wise and desirable?

### **Goal 8: Provide some vaccine to other countries even if it is at the expense of vaccinating some persons in the U.S.**

- ◆ We should choose to help only when our own infrastructure is in place.
- ◆ How would you start to prioritize peoples in other countries?
- ◆ We must decide both the “if” and the “to whom” well in advance of the event.
- ◆ What about those folks interfacing with troops overseas?

### **Goal 9: Protect those who provide homeland security and those who defend against military threats abroad**

- ◆ Government has already deemed that this will happen.
- ◆ This falls into critical services.
- ◆ There is concern that this could “soak” up supply.
- ◆ Military is a first responder and may be able to fill in other services that others cannot in a pandemic.

# Attachment I: Massachusetts Feedback Session

## Things Participants Liked About the Plan As Presented—BOSTON, MA

- We agree with the priority given to health care workers and first responders
- We like that you've included priority status for vaccine production workers and researchers

## Things Participants Didn't Like About the Plan As Presented

<ul style="list-style-type: none"> <li>• Provide for social control: The fact that your priority groups tend to consist of white, English speaking, and middle class people (with only limited access to other populations) will cause social unrest.</li> <li>• [Need for] identification of and outreach to isolated populations (e.g. illegal immigrants).</li> <li>• [Need for] outreach and priority to low socioeconomic groups.</li> <li>• Political spoilers (This is a political distraction).</li> <li>• It doesn't assure equity of distribution. You'll have to help general populations understand the decisions represented here.</li> <li>• We'd rather see simultaneous selection across priority groups.</li> </ul>	<ul style="list-style-type: none"> <li>• Need to give priority to family caregivers.</li> <li>• Need to vaccinate close contacts of infected people.</li> <li>• Need to give priority to the household contacts of those in high risk groups.</li> </ul>	<ul style="list-style-type: none"> <li>• [Need to] maintain transparency of distribution (Public needs to know who gets vaccinated and why. Enforce priority distribution.)</li> <li>• [Need to] keep the public notified of how and why the distribution plan changes.</li> <li>• [Need to] Provide accurate communication from a centralized source to keep people updated on who's being vaccinated? Where? How?</li> <li>• [Need to] Provide people access to accurate information</li> </ul>	<ul style="list-style-type: none"> <li>• Vaccine goals don't place enough emphasis on people who could transmit the flu before they know they are sick.</li> <li>• Personal responsibility.</li> <li>• Use complementary strategies like the pneumonia vaccine.</li> <li>• Encourage responsible media coverage.</li> <li>• Change the assumption on which your goals are based; base goals on assumption of a severe—not a moderate—outbreak.</li> <li>• There's a need for primary prevention. Keep supplies on hand like masks and hand cleaner and provide lots of education.</li> </ul>	<ul style="list-style-type: none"> <li>• Need to prevent deaths and reduce panic among those at highest risk.</li> <li>• Need to be prepared to address resentment and panic (through use of law enforcement and education).</li> <li>• We think that maintaining social order is a high priority to reduce panic (among frontline and medical folks).</li> <li>• We want to hear more about local implementation issues like security of vaccine and viability of split dosing as an option.</li> <li>• Anticipate that social anarchy may break out...require ID verification of those seeking vaccination.</li> <li>• There will be a duty vs. family conflict. Families of first responders and critical workers will need to be vaccinated in order for them to feel confident staying on the job.</li> </ul>	<ul style="list-style-type: none"> <li>• Further revise the "greater than 65" age class issues to take into account quality of life.</li> <li>• Prioritize essential service providers.</li> <li>• Further breakdown the age groups in goal 2, not just "2-65"</li> <li>• Include waste management in utilities.</li> <li>• Support funding for local emergency preparedness. Identify, examine, and revise bureaucracy; support consolidation of community groups, support <b>local emergency preparedness centers</b></li> <li>• Provide more discussion on how plans will be modified demographically following details of outbreak.</li> <li>• Prioritize those living in a highly populated area.</li> </ul>
<p>Separate, but related, comments:</p> <ul style="list-style-type: none"> <li>• Need to look into some kind of accountability for public health officials (e.g. minimum competencies).</li> <li>• We're concerned about social order and communication.</li> <li>• Examine lessons learned from hurricane Katrina.</li> <li>• Plan for worst-case scenario.</li> <li>• Provide alternative "package" to those that don't get vaccine.</li> </ul>		<ul style="list-style-type: none"> <li>• Reverse priorities and distribute vaccine proportionally among priority groups.</li> <li>• Too many people in goal 1...should be just vaccine producers, health/medical providers, and public safety officials.</li> <li>• Two goals go hand in hand, must work on figuring out how to make them go hand in hand.</li> <li>• Who decides?</li> </ul>			
<p><b>RECOMMENDED CHANGE:</b></p> <p><b>Place Higher Value On Fairness</b></p>	<p><b>RECOMMENDED CHANGE:</b></p> <p><b>Give Higher Priority to Critical Caregivers</b></p>	<p><b>RELATED RECOMMENDATION:</b></p> <p><b>Ensure That Plan is Implemented in Manner That Keeps Public Fully Informed</b></p>	<p><b>RELATED RECOMMENDATION:</b></p> <p><b>Implement Prevention Strategies</b></p>	<p><b>RELATED RECOMMENDATION:</b></p> <p><b>Ensure That Plan is Implemented in Manner That Maintains Social Order</b></p>	<p><b>(DID NOT HAVE TIME TO DISCUSS AND CATEGORIZE ABOVE COMMENTS)</b></p>



# Attachment J: Nebraska Feedback Session

## Things Participants Liked About the Plan As Presented—Omaha, NE

- We like the local control, hierarchy of goals.
- We agree with the 2 goals.
- We like that there is a program in place to address this threat.
- The basic plan you've presented is sound. We like its flexibility.
- We like that the Federal Government provides guidelines.
- We like the 2 processes (the goals).
- We like that it's strategic.
- We like that it assures production, distribution, and administration of vaccines.
- We like that the focus is on the group (thereby maintaining social order) over the individual.
- We like that there's state and local input.
- We like government control.
- We like the framework and the structure, but the details need some work.
- We like the hierarchy of the goals as stated.
- We like the "ring" model depicted in this morning's presentation for determining who is at high risk and how this model guides vaccine decision-making.

## • Things Participants Didn't Like About the Plan As Presented—Omaha, NE

<ul style="list-style-type: none"> <li>• Leaves question of what percent of essential people to vaccinate?</li> <li>• Plans to protect food distribution must include production process.</li> <li>• We're concerned about the details of determining those necessary to "maintain social order."</li> <li>• How are you defining "communications"?</li> <li>• It is not specified who will make the decisions. What about families of essential workers?</li> <li>• There is only vague definition of responsibilities.</li> <li>• We'd like a better definition of who is necessary to assure functioning of society.</li> <li>• Need more definition of "functioning of society," currently too subjective.</li> <li>• Clarify who is meant by "key government leaders."</li> <li>• Categories are too vague.</li> </ul>	<ul style="list-style-type: none"> <li>• Need expansion of definition of those at "high risk" to make sure that people taking care of those at high risk are also provided for.</li> <li>• "Ages 2-64" category too large and too diverse.</li> </ul>	<ul style="list-style-type: none"> <li>• Need to start by vaccinating 35-50 year olds in each priority group to protect family and social structure.</li> <li>• Make small amount of vaccine available by lottery for those not in any of the priority groups so that everyone is provided some hope.</li> <li>• Include students and teachers in #1.</li> </ul>	<ul style="list-style-type: none"> <li>• Must be prepared to adjust implementation of allocation as the distribution of vaccine unfolds if public reaction is not as anticipated (e.g. establishing lottery to maintain order).</li> <li>• Concern that differences in state and local decisions in vaccine distribution will cause geographical migration and social disorder.</li> </ul>	<ul style="list-style-type: none"> <li>• We're concerned that your assumptions are based on regular human flu epidemiology and not that of H5N1; H5N1 is NOT following the regular flu sickness pattern!</li> <li>• Eliminate second goal and reword first goal to say, "to be determined based on epidemiology."</li> <li>• Give flexibility to emerging epidemiology of avian flu to who is at risk of death and those infecting others.</li> <li>• We're concerned that school age and day-care children are not included in the identification of those at high risk as depicted in your ring model (only children 2 years and younger are included).</li> </ul>
<p><b>RECOMMENDED CHANGE:</b></p> <p>Be more specific in description of priority groups</p>	<p><b>RECOMMENDED CHANGE:</b></p> <p>Further define who is expected to be in group of those most likely to die</p>	<p><b>RECOMMENDED CHANGE:</b></p> <p>Rework priority groups to add allocation for students, teachers, and a lottery group</p>	<p><b>RECOMMENDED CHANGE:</b></p> <p>Include potential to revise the implementation plan if public does not receive and react to it as anticipated</p>	<p><b>RECOMMENDED CHANGE:</b></p> <p>Eliminate reference to particular age groups and simply say that decisions will be based on the epidemiology</p>

# Attachment K: Oregon Feedback Session

## What changes, if any, would you like to see be made to the vaccination goals? - PORTLAND, OR

<ul style="list-style-type: none"> <li>• Vaccinate food and drug deliverers working door-to-door (to enable retirees to stay home).</li> <li>• Top priority should be given to containing the spread of the disease.</li> <li>• Include home caregivers in same group with healthcare workers as a priority with doctors, etc.</li> <li>• Consider who cannot stay home when deciding who to vaccinate...employees working outside home vs. retired or home-office workers.</li> <li>• Large nursing homes: protect elders in bubble of vaccinated staff (can defer vaccination of residents and prohibit visits from unvaccinated people).</li> <li>• Give high priority to the military and those working abroad where vaccine may be breaking out.</li> <li>• Amend 2A to ensure the protection of those most likely to spread the virus.</li> </ul>	<ul style="list-style-type: none"> <li>• Define functioning of society.</li> <li>• Be more clear about Goal #1; it is too vague. (What is meant by "assuring functioning of society"? How many does it take to do that?)</li> <li>• Protect only a subset of only the critical functions (comment clarified as a suggestion to reverse the goals and provide more specificity as to what is meant by "assuring functioning of society.")</li> <li>• Reverse the order of the goals.</li> <li>• Add a third point that says that we'll serve the minimum number of number of people in the first vaccine group before moving on to the second vaccine group.</li> <li>• If you do #1 you will never get to #2, so the list is really #1.</li> </ul>	<ul style="list-style-type: none"> <li>• Give higher priority to children younger than 18 and their custodial parents.</li> <li>• If the flu is very deadly, protect healthy young adults.</li> </ul> <p>FYI—Separate, but related, issues that were brought up:</p> <p>Warning: You can't deliver vaccine priorities without expecting to have to do A LOT of education and training around the issue. Otherwise, disorder will result.</p> <p>Also:</p> <ul style="list-style-type: none"> <li>• Need pre-pandemic education &amp; training.</li> <li>• Those in group one, after being vaccinated, should not be eligible for anti-viral medications.</li> <li>• Long term problem! Contain at origin with above-market price purchase of potentially diseased birds.</li> <li>• We have little confidence in federal response.</li> <li>• Produce more vaccine.</li> </ul>	<ul style="list-style-type: none"> <li>• Decisions should be made by experts and not political appointees.</li> <li>• In this Post-Katrina environment, we should make sure leadership is non-political and experienced in disaster and public health and safety issues.</li> </ul>
<p><b>RECOMMENDED CHANGE:</b>  <b>Make Decisions Based on Attempts to Limit Exposure</b></p>	<p><b>RECOMMENDED CHANGE:</b>  <b>Provide Greater Definition to the Goals</b></p>	<p><b>RECOMMENDED CHANGE:</b>  <b>Give Higher Priority to the Young and Healthy</b></p>	<p><b>RECOMMENDED CHANGE:</b>  <b>Specify That Those Issuing Guidelines Will Be Experts (Not Politicians)</b></p>

# Attachment L: Evaluation–Methods and Results

## **Evaluation**

This evaluation of the Public Engagement Pilot Project on Pandemic Influenza examines a new mechanism for engaging the public on vaccine policy decisions and explores opportunities and challenges for citizen input. The evaluation of this project is important from two perspectives: First, the results can help inform persons in the public health field interested in engaging citizens in discussions about important policy issues; the evaluation can help answer the question whether obtaining citizen and stakeholder input adds value to important public health decisions. Second, the evaluation results may be useful for persons who study public engagement processes; the evaluation is a case study of one type of citizen deliberation process applied to a public health topic and can yield important lessons for other citizen participation efforts.

The evaluation results presented in this report represent preliminary findings based on the data collected and results analyzed as of early November 2005. At the time of this report, all of the survey data had been collected and preliminary analyses of this data are presented; interviews with organizers, facilitators, observers, citizens and stakeholders were in the process of being conducted, and qualitative information from the interviews conducted are included. The next steps in the evaluation are to conduct additional analyses of the survey data, complete the interviews and conduct a more thorough analysis of the qualitative data, and conduct the next phase of the study: an assessment of how the stakeholder input was used by decision makers.

The evaluation addresses the following major project issues and goals:

1. Participation and recruitment issues:
  - a. Goal: Attract citizens to participate in the process in four locations: Georgia, Massachusetts, Nebraska, and Oregon.
  - b. Goal: Recruit participants who reflect a diversity of perspectives, and demographic characteristics such as age, gender, race/ethnicity, and education.
2. Process issues:
  - a. Goal: Provide information to participants so they have sufficient knowledge about pandemic influenza to adequately consider and discuss the issue of the prioritization of pandemic influenza vaccination for sub-populations (e.g., children, elderly, health care workers, etc.).
  - b. Goal: Design and implement a process that promotes a balanced, honest, and reasoned discussion of the issues while respecting diversity of views.
  - c. Goal: Provide a forum for citizens to deliberate and consider multiple points of view. The evaluation tests the assumption that deliberation affects the opinions and judgments of participants related to prioritization of pandemic influenza vaccination.
3. Product issues:
  - a. Goal: Citizens contribute useful information for the stakeholder deliberations and stakeholders consider and integrate citizen input into their recommendations.
  - b. Goal: Citizen and stakeholder input receives serious consideration by decision makers and adds value to the input already being received from expert groups. A key aspect of the evaluation is to understand how citizen and stakeholder input is used by decision makers in establishing pandemic influenza vaccination priorities.

## Attachment L: Evaluation—Methods and Results (continued)

### 4. Additional outcome issues:

- a. Goal: Citizens are satisfied with the process and believe their input will be considered by decision makers.
- b. Goal: As a result of the process, the relationships among participating stakeholders improve.

## **METHOD**

The evaluation team for this study included staff from the University of Nebraska Public Policy Center and Practicum Limited. The University of Nebraska-Lincoln Institutional Review Board reviewed and approved the evaluation design. This study employs a sequential, mixed method design using quantitative and qualitative information. There are three major methodological components:

1. Pre-post surveys completed by citizens and stakeholders and a comparison group of citizens who were not otherwise involved in discussions about pandemic influenza.
2. Individual interviews conducted with meeting organizers, facilitators, observers, stakeholders and citizens
3. A qualitative evaluation component will be implemented in the future to determine how citizen and stakeholder input is used by decision makers; this component will include document reviews and individual interviews.

### ***Pre-Post Survey***

***Respondents.*** Six groups of people completed the pre-post survey:

1. Stakeholders who participated in the July and September meetings in Washington, D.C.
  - ◆ 28 stakeholders completed the pre-survey on July 13, 2005; 25 stakeholders completed the post-survey on July 14, 2005; 16 stakeholders completed the post-survey on September 8, 2005. Approximately 50 different stakeholders participated in one or both meetings.
2. Citizens who were recruited and participated in the August 27, 2005 Atlanta, Georgia meeting.
  - ◆ 94 citizens completed the pre-survey and 97 citizens completed the post-survey; 101 total citizens participated in the meeting.
3. Citizens who were recruited for and participated in the September 17, 2005 Boston, Massachusetts meeting.
  - ◆ 37 citizens completed the pre-survey and 37 completed the post-survey. 40 citizens participated in the meeting.
4. Citizens who were recruited for and participated in the September 24, 2005 Omaha, Nebraska meeting.
  - ◆ 85 citizens completed the pre-survey and 81 citizens completed the post-survey. 85 citizens participated in the meeting.
5. Citizens who were recruited for and participated in the October 1, 2005 Portland, Oregon meeting.
  - ◆ 36 citizens completed the pre-survey and 27 citizens completed the post-survey. Thirty-five citizens participated in the meeting.
6. Citizens who were recruited for and participated in an October 24, 2005 Kearney, Nebraska citizens deliberation meeting unrelated to pandemic influenza.
  - ◆ A total of 95 citizens completed the pre-survey as a control group.

For each of the six meetings, respondents were asked to complete an informed consent form and

## **Attachment L: Evaluation—Methods and Results (continued)**

voluntarily complete the surveys. After the Kearney, Nebraska meeting, respondents were paid \$5 for their participation. They also gave informed consent. The selection process for the stakeholder and citizens meetings is described in Chapters two and three. Demographic information about respondents is discussed in the Results section on page 72.

**Surveys.** The pre-survey consisted of two sections: 15 multiple-choice questions assessing knowledge about pandemic influenza and a section with four items asking opinions about values, goals and target groups related to priorities for vaccine in the event of a pandemic. The post-survey included these two sections and two additional sections: 1) a series of statements about the quality, fairness and effectiveness of the deliberative process that respondents were asked to rate on a 5 point scale from strongly agree to strongly disagree; and 2) demographic questions. Surveys were pre-tested and modified to improve comprehension of questions and answers. To help reduce response-order bias, three versions of each survey were administered with the order of questions randomly varied in the opinion-questions section. A sample post-survey can be found on page 88.

**Procedures.** Stakeholders and citizens received pre-tests upon registering at the beginning of each meeting. Organizers asked them to find a seat and complete the survey immediately. At the end of the meeting, participants had 15 minutes to complete the post-test.

### ***Individual Interviews***

**Respondents.** The evaluators contacted five groups of people for individual interviews:

1. Stakeholders who participated in the two Washington, D.C. meetings
2. Citizens who participated in the Atlanta meeting
3. Observers from both the Atlanta and Washington, D.C. meetings
4. Facilitators from both the Atlanta and Washington, D.C. meetings
5. Organizers from the Atlanta and Washington, D.C. meetings

The evaluators randomly selected a number of participants from each list and attempted to contact them by telephone and e-mail. Those people who could be reached were selected to participate. For this report, interviews with eight stakeholders, twelve Atlanta citizens, five observers, and two facilitators were used in the analysis. No interviews with Organizers were completed prior to this report.

**Interview Questions.** The interview questions for stakeholders and citizens asked how they perceived the information about pandemic influenza and the quality of the participation; their opinions about distribution of vaccine; their satisfaction with the process; and how they thought policy makers would consider their input. In addition, the stakeholders were asked how they considered the input from the Atlanta citizen deliberation in their decisions and how the deliberations might have changed the relationships among stakeholders. Citizens were asked their opinions about how representative of the general public the participants at the Atlanta meeting were, how they found out about the meeting, and why they participated.

Observers and facilitators were asked whether participants appeared to understand the information about

## **Attachment L: Evaluation—Methods and Results (continued)**

pandemic influenza and their observations about the quality of the deliberations, and, for those who attended the Atlanta meeting, the diversity of the citizen group.

***Procedures.*** Each randomly selected respondent received an e-mail requesting that he or she either schedule an interview with the evaluators or submit a written response to the questions, which were included with each e-mail. Graduate research assistants following an interview protocol conducted the interviews, which were taped and transcribed. A small number of respondents chose to respond by e-mail and were not interviewed.

## **RESULTS**

### ***Participation and Recruitment***

Preliminary observations and findings from the citizen interviews indicate the process was successful at recruiting and attracting citizens to participate in the deliberative process. The goal for the citizen deliberations was to attract 100 participants at the Atlanta meeting and as many as possible at each of the other three state sites. This goal was exceeded in Atlanta which had 103 citizen participants. Participation at the other three sites was 40 for Boston, 85 for Omaha, and 35 for Portland.

Citizens heard about the Atlanta meeting from a variety of sources including the following:

- ◆ Word of mouth from other participants
- ◆ Through an employer
- ◆ From a volunteer program: Hands On Atlanta
- ◆ E-mail from the Atlanta Journal Constitution
- ◆ From his or her city council representative
- ◆ The Voice of Atlanta opinion board
- ◆ Advertisement in the Atlanta Journal Constitution
- ◆ The Alpha Epsilon Delta e-mail listserv (AED is an honor society for pre-med students)

A number of participants indicated they had heard of the meeting through multiple sources.

Participants in the Atlanta meeting identified a variety of motivations for participating. Many indicated they wanted to learn more about pandemic influenza because it is an important and interesting issue. One respondent had just read a book about the 1918 pandemic when she heard about the meeting. Some respondents indicated that they felt it was their civic duty to participate and that it is important to participate in these types of discussions.

As stated by one respondent, *“This is a huge public policy decision. I’ve been reading about it for a year and I’m not even in a health profession.”*

Multiple respondents indicated they felt the process was a unique opportunity for citizens to have input on an important policy topic.

One respondent stated, *“I have a friend who is a doctor, and nothing like this has been done before.”*



## **Attachment L: Evaluation—Methods and Results (continued)**

Some were motivated because of the nature of their profession (e.g., health care) or because of the political party to which they belonged (e.g., Green Party). One person indicated that although she worked in public health, she wanted to participate with the public in this discussion rather than with other health professionals. Some participated as students from a local university. One student, a pre-med major, said she had heard a presentation on public policy regarding pandemic influenza and was interested in public health as a profession.

Participants appeared to represent a diverse mixture of demographic characteristics and perspectives. For participants who completed the post-survey, the demographic information indicates diversity within the sample in age, gender, race/ethnicity, and education, although participants were not representative of the general population. Table 1 shows age percentages for all four citizen deliberation sites, indicating a cross-section of ages with the largest age group at each of the four sites as the 55 – 64 category. Eighteen to 34-year-olds were under-represented across all four sites.

Table 1  
Percentage of respondents by age for each citizen site

<b>Age</b>	<b>Atlanta (N=97)</b>	<b>Boston (N=37)</b>	<b>Omaha (N=81)</b>	<b>Portland (N=27)</b>
18-24	10.8%	3.2%	13.7%	0.0%
25-34	3.6%	6.5%	13.7%	5.3%
35-44	20.5%	12.9%	16.4%	26.3%
45-54	25.3%	25.8%	21.9%	21.1%
55-64	27.7%	32.3%	21.9%	31.6%
65+	12.0%	19.4%	12.3%	15.8%
Total	99.9%	100.1%	99.9%	100.0%

Table 2 shows gender percentages for each of the four sites, indicating that participants in all four sites were predominately female. Portland, at 42.1% men, had the most equal gender distribution.

Table 2  
Percentage of respondents by gender for each citizen site

<b>Gender</b>	<b>Atlanta</b>	<b>Boston</b>	<b>Omaha</b>	<b>Portland</b>
Male	31.3%	22.6%	23.3%	42.1%
Female	68.7%	77.4%	76.7%	57.9%
Total	100%	100%	100%	100%

**Attachment L: Evaluation—Methods and Results (continued)**

Table 3 shows race/ethnicity for each site and indicates there was a mix of racial/ethnic diversity across the four sites.

Table 3  
Percentage of respondents by race/ethnicity for each citizen site

<b>Race/Ethnicity</b>	<b>Atlanta</b>	<b>Boston</b>	<b>Omaha</b>	<b>Portland</b>
Hispanic	3.6%	6.5%	4.1%	0.0%
White	67.5%	77.4%	84.9%	77.8%
African American	20.5%	9.7%	8.2%	2.8%
Asian	3.6%	3.2%	1.4%	2.8%
Native American	2.4%	0.0%	0.0%	2.8%
Other	2.4%	3.2%	1.4%	2.8%
Total	100.0%	100.0%	100.0%	100.0%

Table 4 shows education levels across the four sites and indicates that education levels are higher than the general population. None of the sites had respondents whose highest level of education was less than a high school degree. At each of the sites, at least 73% of respondents had at least a college degree.

Table 4  
Percentage of respondents by education level for each citizen site

<b>Level of Education</b>	<b>Atlanta</b>	<b>Boston</b>	<b>Omaha</b>	<b>Port-</b>
Less than high school	0.0%	0.0%	0.0%	0.0%
Some high school	0.0%	0.0%	0.0%	0.0%
High school graduate	7.2%	0.0%	1.4%	0.0%
Trade or technical school	1.2%	3.2%	1.4%	0.0%
Some college	15.7%	19.4%	17.8%	26.3%
College graduate	39.8%	22.6%	37.0%	47.4%
Graduate school	36.1%	54.8%	42.5%	26.3%
Total	100.0%	100.0%	100.1%	100.0%

For the most part, citizens believed that the participants reflected a diversity of demographics and views. A number of respondents from the Atlanta meeting said that they thought the group was diverse in terms of culture, race, age, gender, and areas across Atlanta. Some respondents perceived a diversity of political views, with representation from both conservatives and liberals.

Some respondents indicated that certain groups were not well-represented, including Hispanics, Asians, people of color, poor persons, blue-collar families, and the elderly.

As one person noted, *“I thought it represented a diverse mix of middle, upper-class people. I don’t think you got lower-class, vulnerable populations.”*

## **Attachment L: Evaluation—Methods and Results (continued)**

One Atlanta citizen suggested these types of forums would need to take place at the locations where under-represented groups live/gather to get their participation, such as an assisted-living facility for the elderly, or lower-income neighborhoods to reach the poor. Other respondents indicated that while the whole group was representative, the small group they participated in lacked representation of certain types of individuals.

Observers and facilitators also thought that there was good diversity at the Atlanta meeting.

*As one observer stated, “I thought it reflected a very diverse mix. My table had one young white male college student, a young 20s black woman, a young woman with Hispanic background, one 60ish retired white woman, a late 60s-early 70s white man, a 50s woman, a 40s black woman and a 50s white man.”*

Another observer was pleased the group had diversity of family representation such as single parents and grandparents. Observers thought that, although the group was diverse based on demographic factors, participants were unusually intelligent and articulate; they were unsure how well participants represented the broader society in this respect. A common theme among observers was how impressive the participants were in grasping the concepts and engaging in informed discussion about complex policy issues. As with the citizens, observers and facilitators also noted that the group consisted mostly of upper and middle classes.

### ***Citizen and Stakeholder Knowledge***

Survey results indicate the D.C. Stakeholders had a relatively high level of knowledge about pandemic influenza before engaging in the deliberative process or receiving information at the meeting. The average percentage of correct answers on the pre-survey was 74.3%. After information was provided and stakeholders had an opportunity to discuss the issues, knowledge about pandemic influenza increased marginally; the average percentage of correct answers on the post-survey increased to 76.7%. Although the number of stakeholder respondents was too small to test for statistical significance (pre survey N = 27, post survey N = 25), substantial increases were found on five of the 15 questions between the pre-survey and the post survey.

Citizens, as a group had less knowledge than stakeholders of pandemic influenza as indicated on the pre-survey. The percentage of correct answers on the pre-survey was 52.1% for Atlanta, 42.7% for Boston, 59.5% for Omaha, and 59.3 for Portland. The post-survey results indicated that statistically significant increases in knowledge ( $p < .001$ ) occurred at all four citizen sites. Knowledge levels, although not quite to the level of the Stakeholders, were much closer after information was provided and participants deliberated: 71.4% for Atlanta, 67.5% for Boston, 74.6% for Omaha, and 73.3% for Portland. It is interesting to note that although the citizens in Boston, Omaha and Portland did not receive as extensive information about pandemic influenza as the Atlanta citizens, their knowledge based on the post-survey was at approximately at the same level. Knowledge levels among citizens became more consistent as indicated in a reduction of the standard deviation (e.g., for Atlanta, pre-survey standard deviation was 18.5, while post-survey standard deviation was 13.3).

**Attachment L: Evaluation—Methods and Results (continued)**

An item analysis indicates knowledge on many of the individual questions increased significantly from pre-survey to post survey ( $p < .05$ ). The Atlanta results are representative of the four citizen groups. Table 5 shows that knowledge on nine of the 15 questions increased significantly, one decreased significantly, three increased but not at a significant level, and one decreased slightly. These results indicate the process designed by the project organizers was successful at increasing the level of knowledge of citizens.

Table 5  
Change in knowledge for Atlanta citizens

Question Topic	% correct pre-survey	% correct post-survey
Reason for getting the flu	86.2%	90.7%
Average influenza hospitalizations	34.0%	46.4%*
Benefits of antiviral drugs	69.1%	57.7%**
Average deaths from influenza	57.4%	86.6%*
Priority group for vaccine last year	87.2%	86.6%
Effectiveness of vaccine	69.1%	73.2%
Length of vaccine production	46.8%	90.7%*
Frequency of pandemic	40.4%	80.4%*
Cause of pandemic	67.0%	76.3%
Last pandemic	41.5%	79.4%*
Type of avian influenza virus	28.7%	84.5%*
Pandemic vs. epidemic	72.3%	89.7%*
Percentage vaccinated each week	54.3%	74.2%*
Potential illnesses from pandemic	12.8%	14.4%
Potential deaths from pandemic	12.8%	26.8%*

\* Increase significant at  $p < .05$

\*\* Decrease significant at  $p < .05$

The pre-post surveys may not be a true reflection of the change in knowledge resulting from the process. It is possible participants become more aware of news articles and read materials between the time they chose to participate in the process and the deliberation. Observers noted that a number of participants in the citizen deliberations brought newspaper articles with them or mentioned that they had read books or other materials prior to and in preparation for the deliberation. To test this hypothesis, citizens in another deliberative process, unrelated to pandemic influenza, in Kearney, Nebraska were asked to complete the pandemic influenza survey. This group of citizens (control group) is similar to citizens in the pandemic influenza deliberations in that they were motivated to participate in a deliberative process; unlike the citizens in the pandemic influenza deliberations, however, they were not sensitized to the topic prior to taking the survey. Table 6 provides a comparison of the pre-surveys completed by the four pandemic influenza citizen groups to the same survey completed by the control group. The results support the hypothesis. For ten of the knowledge questions, the pandemic influenza citizen groups had substantially

**Attachment L: Evaluation–Methods and Results (continued)**

higher scores than the control group indicating they had greater knowledge than similar citizens before they deliberated or received information about pandemic influenza at the meetings. Another explanation may be that persons with pre-existing knowledge about influenza elected to participate in the pandemic influenza meetings.

Table 6  
Comparison of percent of knowledge questions answered correctly  
Between control group and four citizens pandemic influenza groups pre-surveys

Question Topic	Control Group % correct (number)	Four Pandemic Groups % correct (number)
Reason for getting the flu	73.7 (70)	83.9 (209)
Average influenza hospitalizations	36.8 (35)	33.7 ( 84)
Benefits of antiviral drugs	68.4 (65)	67.9 (169)
Average deaths from influenza	35.8 (34)	53.0 (132)
Priority group for vaccine last year	92.6 (88)	88.0 (219)
Effectiveness of vaccine	60.0 (57)	67.1 (167)
Length of vaccine production	29.5 (28)	57.0 (142)
Frequency of pandemic	16.8 (16)	45.0 (112)
Cause of pandemic	65.3 (62)	70.7 (176)
Last pandemic	11.6 (11)	45.8 (114)
Type of avian influenza virus	12.6 (12)	40.6 (101)
Pandemic vs. epidemic	47.4 (45)	71.9 (179)
Percentage vaccinated each week	42.1 (40)	52.2 (130)
Potential illnesses from pandemic	17.9 (17)	18.9 ( 47)
Potential deaths from pandemic	15.8 (15)	13.7 ( 34)

The perceptions of the stakeholders and citizens verify the quantitative results. Overall, stakeholders and citizens believed they had enough information to have well-informed opinions about vaccine distribution. On a 1 to 5 scale, with 1 representing strongly disagree and 5 representing strongly agree, average scores were as follows:

1st Washington, D.C.	3.21
2nd Washington, D.C.	4.36
Atlanta	4.40
Boston	4.14
Omaha	4.04
Portland	4.05

## **Attachment L: Evaluation—Methods and Results (continued)**

Boston, Omaha and Portland have similar results, which is not surprising since citizens at all three sites received about the same type and amount of information through similar formats. In contrast, the stakeholders who met in Washington D.C., who had expertise prior to the meeting and received the most extensive information about pandemic influenza at their meeting, felt less sure that they had enough information to have well-informed opinions after their initial meeting when compared to the Atlanta citizens (D.C. Mean = 3.21; Atlanta Mean =4.40). It is possible that the stakeholders had a better understanding of the deficits in their knowledge.

Based on interviews, stakeholders believed they had a good grasp of the information about pandemic influenza after the two meetings. Many of the stakeholders indicated they had substantial knowledge about pandemic influenza because of their professions or backgrounds, which helps explain the high pre-survey scores.

As stated by one individual, *“All of the information that was given was information I already had at my disposal. There were a few things I think that I might have picked up. But having dealt with this for a while, I think I have a pretty good background.”*

Other stakeholders, however, believed they learned quite a bit from the information presented that helped fill gaps in their knowledge. Stakeholders generally believed that the information was presented clearly at the meeting and represented about the right volume of information.

However, one person said, *“I personally, from my position, felt that there was probably information that the public engagement group should have been given, so they could understand at least where the medical recommendations came from.”*

Another stakeholder indicated that there may not have been enough information provided about the possible range of severity of potential pandemics, stating, *“I think the planners made a mistake by limiting the information they provided to a mid-range pandemic, since they have no real basis for presuming that the next pandemic would not be as severe as the 1918 pandemic, or more severe.”*

Some of the stakeholders referred to the ethics discussion as a particularly useful part of the process. A common response among stakeholders was that having adequate information about pandemic influenza was essential to informed and meaningful deliberation.

One stakeholder observed, *“This information put everyone on a fairly identical platform in terms of ideas and wisdom going into the deliberations. I think you need everybody on a fairly even playing field.”*

Citizens from Atlanta also indicated they understood the information presented during the meeting. Some indicated they knew about pandemic influenza before the meeting.

*“I understood it really well, but I have an advantage because I am [a] pre-med [student].”*

A common theme among citizens was a belief that the information was effectively presented.



## **Attachment L: Evaluation—Methods and Results (continued)**

As one citizen said regarding the background materials, *“I think that what they gave us was fairly easy to understand.”*

Another said regarding the presentation and the written information, *“It was straightforward and at the appropriate level.”*

While another said, *“It truly informed the discussion, and I thought it was really well done.”*

Citizens also appreciated the resource experts that were available, indicating that their questions were answered well.

As one citizen said, *“If I didn’t understand the information, a doctor from CDC was sitting with us at our table that was able to answer all our questions.”*

Participants indicated the information helped them deliberate based on facts rather than opinions. One person made an analogy to the way juries are presented information and asked to reach a decision.

Observers appeared to confirm that the citizens seemed well-informed.

As stated by one observer, *“One of the clearest impressions I had of the group was that it sought to be as objective and informed as it could be.”*

Another said, *“I am confident participants understood the information ... and were able to engage in an intelligent conversation on the issue.”*

One observer, however, was more cautious, *“The level of understanding at the end of the meeting was good but not excellent. It was better than the average citizen.”*

Some observers noticed citizens seemed to refer to materials appropriately during their deliberations and received good answers from experts that were useful to the discussion.

### ***The Quality of Deliberations***

The post-surveys indicate stakeholders and citizens generally believed the process was of high quality. Table 7 shows average scores for ratings of the process on a scale 1 to 5, with 1 representing strongly disagree and 5 representing strongly agree. For the first six items, a higher quality process is associated with a higher score. For the last two items, a higher quality process is associated with a lower score.

**Attachment L: Evaluation—Methods and Results (continued)**

Table 7  
Average ratings on process by site

Statement	DC1	DC 2	Atl	Bos	Oma	Por
I felt comfortable talking	4.78	4.57	4.85	4.71	4.28	4.68
I think other people felt comfortable talking	4.71	4.71	4.73	4.69	4.19	4.53
This discussion was fair to all participants	4.71	4.93	4.74	4.50	4.18	4.26
I think this process helped me better understand the types of trade-offs	4.54	4.69	4.72	4.74	4.22	3.79
I think this process has produced credible, relevant, and independent information	4.17	4.79	4.61	4.45	4.05	4.47
I think this process produced a valuable outcome	3.91	4.64	4.43	4.03	3.78	4.11
Important points were left out of our discussion	3.17	2.64	2.53	3.07	3.32	3.79
One person or small group of persons dominated the discussion	1.88	1.71	1.73	2.07	3.12	2.42

From these results, it is evident that participants at all six meetings felt comfortable talking, believed others felt comfortable talking, and thought the discussion was fair to all participants. Citizens thought the process helped them understand trade-offs, although citizens at the Portland meeting were somewhat less likely to indicate positively to this question. Respondents at all locations tended to believe that the process produced credible, relevant and independent information.

Most locations had somewhat lower scores for the statement, “I think this process produced a valuable outcome,” although participants still generally agreed with this statement. Many individuals felt that important points had been left out of the discussion; in fact, in four locations, respondents agreed with this statement more than they disagreed. At most sites, respondents believed it was not true that a person or small group dominated the discussion. However, in Omaha, the average respondent agreed that a person or group had dominated the discussion.

Generally for all groups, the standard deviation was highest for the last two questions, indicating a higher level of disagreement among participants. In summary, based on the survey, respondents agreed in all sites that the process employed at each meeting was high quality. The exception was participants in the shorter Boston, Omaha and Portland meetings felt that important points were left out, although it is unclear what points they thought were missing.

From the interviews, stakeholders and citizen responses were consistent with the numerical data. There seemed to be general agreement by stakeholders that everyone had a chance to participate in the discussions and that there were substantial efforts to make sure all participants were heard.

## Attachment L: Evaluation—Methods and Results (continued)

One stakeholder said, *“What I liked about it was there were no shrinking violets. People were quick to say ‘I don’t get this; can you explain it to me better?’ Or ‘I totally disagree.’ I know that in the working group I was in, everyone spoke loud and long.”*

Some stakeholders thought a few people who had been in health-related fields a long time dominated some of the conversation, but this may have been because others looked to them for expertise. Some thought there were a few people that were quieter than others, but everyone participated to some extent and that people felt more comfortable over time. Some stakeholders identified the facilitation as helping ensure participation by all participants.

As one stated, *“In fact, the facilitation was so well done that no one ever dominated the discussion. I’ve been in many meetings like that where people became frustrated that people are allowed to dominate the discussion, and they just withdrew.”*

Observers and facilitators had interesting insights into the process. There was agreement among observers and facilitators the discussion was balance and everyone had a chance to participate. The balance appeared to be due, in large part, to the facilitation.

As one facilitator noted, *“Both the participants and I solicited comments from the few who seemed reticent, in the beginning, about expressing their views. Also, because workshop rules were established at the outset, participants knew what was expected”*

An observer agreed, noting, *“The facilitators seemed to be moving the discussions along very well and opening up spaces for everyone to participate. At the same time, it was clear that opening statements tended to exercise a good deal of force on the conversation.”*

Another observer recognized the value and quality of the facilitation, *“The presence of a small-group facilitator helped to ensure that everyone had an equal voice at the table. For instance, at my table, one participant made somewhat controversial statements that the rest of the participants strongly disagreed with. Having a small-group facilitator ensured that the controversial participant was respected in the process.”*

Observers and facilitators agreed that they thought participants shared their true beliefs during the discussion. One observer shared this observation:

*“It seemed to me that participants were trying, as well as they could, to seem informed and objective. This meant that they didn’t appeal very much to personal experience, or to emotion, when justifying their views. This is uncommon in this type of setting, especially when participants are dealing with a complicated issue about which they know little.”*

There was disagreement about whether the citizens in Atlanta had enough time to adequately deliberate. About half the observers interviewed thought the amount of time was adequate and about half thought the time was not adequate. One observer who thought time was inadequate said:

*“There is never enough time in a single day to engage in this type of discussion. I think people had time to voice their views. I’m not certain they had time to fully incorporate the views of others and ultimately, to choose what ought to be done about the issue.”*

## **Attachment L: Evaluation—Methods and Results (continued)**

Observers also disagreed about the extent to which participants carefully considered other points of view. Some observers thought participants had considered the views of others and would alter their own views based on these perspectives. As one person observed,

*“They were very respectful – sometimes even incorporating and changing their own viewpoint based on what others brought up. Even when they disagreed, they asked for further clarification and reasons for that viewpoint.”*

Other observers, however, thought there was not sufficient time to fully understand different and multiple perspectives, stating:

*“There was only enough time for people to express themselves, less time for them to think through the position of others. In my experience, this [thinking through others’ positions] often happens after an event – on the way home after an event or while talking with a friend or spouse about what transpired.”*

Observers had other impressions about the process such as the following:

- ◆ The process resulted in creative suggestions such as raising awareness about pandemic influenza through the Oprah or Dr. Phil talk shows, or a reality TV series.
- ◆ Overall, impressed with how the public was well informed, how people grasped information quickly and knew what had to be done.
- ◆ It appeared that even if one’s point of view did not prevail, if a person was heard and part of the process, they had ultimate comfort in the decision.
- ◆ At times the citizens appeared to be “unemotional and perhaps even overly rational – not at all what I would expect from such a group.”
- ◆ “People seem to be very thoughtful in articulating their own views. Collectively, they were less thoughtful in interrogating group assumptions.”
- ◆ Some citizens and stakeholders questioned the premise of the charge regarding prioritizing limited quantities of vaccine and would have rather discussed how more vaccine could be produced.

### ***The Impact of Deliberations on Opinions about Vaccine Distribution***

Survey results indicate some opinions regarding social values, goals, and priority groups changed for stakeholders and citizens after they received information and deliberated about vaccine distribution. For stakeholders, opinions on six of the 10 social values changed significantly or at levels approaching statistical significance from the pre-survey to the post-survey. As shown in Table 8, Equality became more important while Freedom, Compassion, National Security, Nationalism, and Independence became less important (the lower the score, the higher the priority). If the sample size were larger, we believe the results would have reached statistical significance. Also, as indicated by the standard deviations, there was greater agreement at the end of the stakeholder meeting about the values of Freedom, Equality, Societal Contribution, and Independence, but less agreement about National Security, Utilitarianism, and Social Order.

Table 8  
Changes in social value ratings by stakeholders

<b>Social Value</b>	<b>N</b>	<b>Pretest Mean (Std. Dev.)</b>	<b>Posttest Mean (Std. Dev.)</b>	<b>ANOVA p-value</b>
Freedom	15	4.33 (1.877)	5.67 (1.047)	.021
Equality	13	4.15 (2.075)	2.92 (1.553)	.055
Compassion	19	2.79 (1.584)	3.37 (1.707)	.053
Societal Contribution	17	4.82 (1.976)	5.18 (1.704)	.534
National Security	15	2.73 (1.534)	3.87 (2.326)	.021
Nationalism	15	4.13 (1.846)	5.13 (1.995)	.149
Independence	15	5.47 (1.885)	6.20 (1.320)	.094
Social Justice	15	1.82 (1.185)	1.71 (1.105)	.718
Utilitarianism	17	1.71 (0.686)	1.59 (1.004)	.579
Social Order	19	2.11 (1.049)	2.21 (1.316)	.695

The pre-post surveys from the citizen deliberations in Atlanta, Boston, Omaha, and Portland also indicated changes in opinions about social values, but not in consistent ways. Statistically significant findings for Atlanta indicated Nationalism and Social Order became more important while Independence became less important (see Table 9). For Boston, Societal Contribution became more important while Compassion, National Security, and Independence became less important. In Omaha, Societal Contribution, Nationalism, and Utilitarianism became more important while Equality and Independence became less important. In Portland, Equality, Compassion, and Social Justice became less important.

Table 9  
Changes in social value ratings by Atlanta citizens

Social Value	N	Pretest Mean (Std. Dev.)	Posttest Mean (Std. Dev.)	ANOVA p-value
Freedom	84	4.37 (2.040)	5.68 (1.851)	.124
Equality	80	3.60 (1.991)	3.76 (1.931)	.385
Compassion	84	3.01 (1.814)	2.82 (1.629)	.292
Societal Contribution	84	4.62 (1.849)	4.45 (1.978)	.434
National Security	84	2.94 (2.100)	3.06 (1.868)	.540
Nationalism	84	4.24 (2.036)	3.80 (2.017)	.024*
Independence	84	4.55 (1.996)	5.08 (1.971)	.013*
Social Justice	87	2.13 (1.445)	2.26 (1.544)	.387
Utilitarianism	84	1.99 (1.340)	1.70 (1.278)	.069
Social Order	86	2.27 (1.683)	1.93 (1.281)	.040*

\* p<.05

Significant changes were also found for opinions about the goals of vaccination and the priority groups for vaccination. Atlanta is illustrative; for ranking of goals, *minimizing spread of the disease* and *maintaining national security* were both ranked significantly lower at the end of the deliberative process while for priority groups, the category of *those most likely to pass on to the community* was ranked significantly lower. It should be noted that for most of the goals and groups, there were not statistically significant changes. The other sites also had significant changes on some of the goals and priority groups, although these changes were not consistent across sites. Also, as with the Atlanta meeting, most opinions regarding goals and groups did not change significantly from the pre-survey to the post-survey.

Although overall the groups exhibited little shift in opinions, some of the individuals indicated that their personal opinions changed as a result of the process.

As stated by one of the stakeholders, “*In some ways they [her opinions] did change. There was a lot of heated debate about the sick and the elderly, and in the end I was more comfortable about giving the vaccine to [people at] the highest risk. At the start, I believed it was better to give the vaccine to the people who had the most life ahead of them.*”



## **Attachment L: Evaluation—Methods and Results (continued)**

Another stakeholder stated, *“It was a great learning experience for me. When you learn new things, you tend to change your opinion a little, and I did.”* One of the citizens from the Atlanta meeting thought that her opinions had changed, stating, *“[My opinions changed] to an extent because I was more informed about other things to consider, not only children and elderly, but also caregivers and different categories like medical personnel, first responders and military.”*

### ***Use of the Input by Policymakers***

Citizens and stakeholders generally expressed their belief the input provided would be used by policymakers. They also believed the deliberative process would increase the public’s support of the decision that would be made about vaccine distribution. Table 10 shows ratings for these two questions (on a 1 to 5 scale with 5 being strongly agree and 1 being strongly disagree) across all sites. At all sites, there was stronger agreement that the process would increase public support for the decision than that decision makers would use the input.

Table 10  
Ratings of perceptions about the impact of the input by site

Statement	DC1	DC2	Atl	Bos	Oma	Por
I think this process will increase	3.78	4.07	4.29	4.16	3.93	4.05
I think public officials will use our	3.59	3.64	3.86	3.71	3.63	3.67

Stakeholders were asked to what extent they considered the results from the Atlanta citizens meeting in their decisions. Responses from stakeholders regarding this issue were mixed. Most stakeholders who were interviewed indicated they considered the citizen input very seriously.

One stakeholder said, *“I considered them heavily, but they actually matched up with my beliefs, so it didn’t really change anything.”*

One of the stakeholders who attended the Atlanta meeting as an observer said, *“I learned a lot in Atlanta and I think I incorporated their thoughts quite a bit.”*

Referring to two Atlanta citizens who attended the September stakeholder meeting, another stakeholder said, *“I really thought that was such a fabulous part of the whole process, and I was really glad to have those two people there to really give their perspective. That to me was the validating part of this whole process.”*

Others seemed to have high regard for the citizen group input, but used their own judgment in coming to a decision; as one stakeholder said, *“I think it was very important to hear what they had to say and how they went through the process. I was very impressed with what they did. I was aware that they were missing some information.”*

Still other stakeholders indicated they did not consider the citizen input. As stated by a stakeholder, *“It was interesting to hear, but it didn’t influence my thinking much.”*

Others indicated that they had already made up their minds at the July stakeholder meeting and, therefore, the citizen feedback at the second stakeholder meeting in September had little impact.

***Additional Outcomes from the Process***

**Who Should Decide Priorities?** Stakeholders and citizens were asked who, or what entity, should decide priorities for influenza vaccine. At the stakeholder meeting and all four citizen deliberation sites, the highest rated entity for making this decision in the pre-meeting survey was the Centers for Disease Control and Prevention (CDC). After the deliberations, the CDC received lower ratings at all sites except Atlanta, where the CDC is located. State and local health departments received higher post-deliberation process ratings at all sites except Atlanta. In fact, in Boston and Portland, citizens gave state health departments the highest ratings after the participatory process. A possible explanation is that citizens felt empowered through the deliberations and, as a result, favored more local control of vaccine decisions. Along this same line, since the Centers for Disease Control and Prevention are located in Atlanta, it is possible that Atlanta citizens viewed the CDC as more of a local entity than a federal agency and rated it higher after the deliberations.

Another finding is that while the number of persons who indicated they did not have enough information to decide decreased after deliberations in all four citizen groups, the number of stakeholders who indicated they did not have enough information to decide actually increased after the deliberations and information dissemination even though the stakeholders included experts on pandemic influenza and received the most amount of information on the topic. Table 11 shows the ratings on the pre and post surveys for all sites.

Table 11  
Pre and post survey percentages ratings of who should decide vaccine distribution by site

Organization	DC		Atlanta		Boston		Omaha		Portland	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
White House	7.7%	<b>4.8%</b>	2.2%	<b>1.1%</b>	3.1%	<b>3.2%</b>	0.0%	<b>2.6%</b>	2.9%	<b>0.0%</b>
CDC	61.5%	<b>47.6%</b>	67.4%	<b>74.2%</b>	43.8%	<b>29.0%</b>	52.0%	<b>46.1%</b>	45.7%	<b>29.6%</b>
Other Fed Agency	3.8%	<b>4.8%</b>	0.0%	<b>3.2%</b>	3.1%	<b>3.2%</b>	1.3%	<b>0.0%</b>	2.9%	<b>11.1%</b>
State Health Dept.	11.5%	<b>19.0%</b>	4.3%	<b>4.3%</b>	12.5%	<b>35.5%</b>	9.3%	<b>26.3%</b>	17.1%	<b>48.1%</b>
Local Health Dept	0.0%	<b>4.8%</b>	1.1%	<b>1.1%</b>	3.1%	<b>3.2%</b>	2.7%	<b>15.8%</b>	5.7%	<b>3.7%</b>
Doctors and Nurses	0.0%	<b>0.0%</b>	2.0%	<b>2.2%</b>	6.3%	<b>19.4%</b>	9.3%	<b>5.3%</b>	5.7%	<b>0.0%</b>
Individuals Themselves	3.8%	<b>0.0%</b>	4.3%	<b>4.3%</b>	3.1%	<b>0.0%</b>	0.0%	<b>1.3%</b>	2.9%	<b>0.0%</b>
Not enough info to decide	11.5%	<b>19.0%</b>	18.5%	<b>9.7%</b>	25.0%	<b>6.5%</b>	25.35	<b>2.6%</b>	17.1%	<b>7.4%</b>

**Relationship Among Stakeholders.** Stakeholders were asked whether the deliberative process changed the relationship among the stakeholders. Most respondents thought that the process had changed their relationship with other stakeholders. These changes included strengthening the relationships, creating a better understanding of each other's thoughts and priorities, bringing stakeholders closer together, and creating relationships that did not exist prior to the process. As one stakeholder observed, *"We were talking with groups we haven't talked to before. I think it improved the relationship. This could be a reflection of the fact that you had people who were listening to each other at this meeting."*

One respondent did not think there was any change in the relationships among stakeholders, stating, *"I'm not aware that it did, nor did I understand that to be the goal."*

Another stakeholder said, *"I think all the relationship issues were beneficial. I actively make use of resources I learned about through the experience and have openly and actively communicated with some of the other stakeholders through my job."*

## **Public Engagement Pilot Project on Pandemic Influenza Post-Meeting Evaluation Survey**

Thank you for taking a few minutes to fill out this survey.

This survey has two short sections added on to the same questions you answered at the beginning of the meeting. Again, your name will not be connected to your answers.

Your responses are absolutely necessary for this research, so thank you again for taking the time to thoughtfully complete this survey before you leave.

Please fill in the boxes below with the year you were born followed by the last four digits of your home phone number. Please use the same numbers you used when you took the Pre-Meeting Survey.

### **Your Confidential ID Number**

1	9						
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**Your Year of Birth**

**Last Four Digits of  
Your Home Phone Number**


**Attachment L: Evaluation—Methods and Results (continued)**

**Section I: Opinions about Influenza Vaccine Policy**

**We are interested in your personal opinions regarding how you might set priorities for vaccination in the event of an influenza pandemic.**

- (1) Imagine you are in a position to recommend to policy-makers the most important values to consider when making decisions about priorities with respect to the distribution of flu vaccine. Please rate the importance to you of the social values in the following list with this in mind.

⇒ First look over the whole list. Then, decide which value is most important to you in making these decisions and circle the number “1” for this value. Then, decide which value is least important to you and circle the number “7” for this one. Using these two values – the most important one and the least important ones – to anchor the rest of your choices, rate all the remaining items on the scale of 1 to 7 (again, where 1 is most important and 7 is least important). You can use 1 or 7 more than once.

SOCIAL VALUE							
	Most Important						Least Important
<b>Social Order</b> – Policies should minimize the risk of chaos in the event of an influenza pandemic.	1	2	3	4	5	6	7
<b>Freedom</b> – Policies do not infringe on personal freedoms of individuals to congregate, travel, or work.	1	2	3	4	5	6	7
<b>Utilitarian</b> – Vaccine policies should ensure the greatest good for the greatest number of people.	1	2	3	4	5	6	7
<b>Equality</b> – Everyone has an equal chance to the vaccine.	1	2	3	4	5	6	7
<b>Social Justice</b> – The vaccine should be available to individuals regardless of ability to pay or access the vaccine.	1	2	3	4	5	6	7
<b>Independence</b> – Allowing individuals to access vaccine without government restrictions should be a priority.	1	2	3	4	5	6	7
<b>National Security</b> – Ensuring the security of the United States is a priority in the event of an influenza pandemic.	1	2	3	4	5	6	7
<b>Compassion</b> – Persons most in need, such as the sick and frail, are protected.	1	2	3	4	5	6	7
<b>Nationalism</b> – Policies are based on what is best for the United States.	1	2	3	4	5	6	7
<b>Societal Contribution</b> – Priority is given to those who contribute most to society.	1	2	3	4	5	6	7

- (2) Imagine you had to decide about priorities in the event of pandemic influenza when there is a limited supply of the vaccine. How would you rank order the following goals from ‘1,’ highest priority, to “8,” lowest priority?

⇒ Please use each number, 1 through 8, only once.

**Attachment L: Evaluation—Methods and Results (continued)**

Goal	Your Ranking
Treat all persons the same regardless of status	
Maintain social order	
Ensure adequate distribution of vaccine and antiviral medicines	
Maintain critical health care services	
Maintain national security	
Maintain economic productivity	
Minimize deaths due to influenza	
Minimize the spread of influenza	

- (3) If there is a pandemic flu outbreak and there is only a limited supply of vaccine, it will have to be administered to priority groups first. While the goal is to eventually vaccinate everyone, it may not be possible to do it all at once.

⇒ Listed below are eight population groups. Please rank the groups from 1 to 8 (“1” being the highest priority, “8” being the lowest priority), in order of which groups you currently believe should receive priority for getting limited flu vaccines. Please use each number 1 through 8 only once.

Group	Your Ranking
People who provide vital community services	
People at highest risk of dying from influenza	
People who provide health care	
People most likely to pass on influenza to others in the community	
People most likely to transmit viruses to those who are at high risk of dying from influenza	
People who request the vaccine (first come, first served)	
People who implement pandemic response activities	
People who provide the greatest economic benefits to the community	

If there is a group not listed above that should be considered as “high priority” for vaccination during a pandemic flu outbreak, please indicate the group below:

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- (4) If there is a shortage of flu vaccine during a pandemic (a global influenza outbreak), who should decide who gets the flu vaccine?

⇒ Please check only one box.

- Your local health department
- State health department
- White House
- Individual doctors and nurses
- Centers for Disease Control and Prevention (CDC) - a federal agency
- Other federal agency [PLEASE SPECIFY] \_\_\_\_\_
- Individuals themselves
- I don't have enough information to decide



**Section II: Knowledge About Pandemic Influenza (Flu)**

**We are interested in what you know right now about influenza, vaccines, past influenza pandemics and potential future influenza pandemics.**

⇒ For the following questions, please select the answers you believe are correct, given what you know about influenza right now.

(5) Why can people get the flu year after year?

- Because viruses that cause the flu have not been identified
- Because viruses that cause the flu change to escape the human body's immune system
- Because there is no vaccination against the flu virus
- Because there is no anti-viral medication to treat flu symptoms
- Don't know

(6) About how many people do you think are hospitalized in a typical year from flu in the United States?

- 1,000
- 10,000
- 100,000
- 200,000
- Don't know

(7) Antiviral drugs are used to treat the flu. Check each of the item(s) below that describe why antiviral drugs are important:

- They can reduce the symptoms of the flu
- They can shorten the time you are sick from the flu by 1 or 2 days
- They can keep you from getting the flu
- They can make you less contagious to others
- Don't know

(8) About how many people do you think die in a typical year from flu in the United States?

- 1,500
- 35,000
- 150,000
- 250,000
- Don't know

**Attachment L: Evaluation—Methods and Results (continued)**

- (9) Which of these population groups was **NOT** a priority group for vaccination during the 2004-05 flu season?
- Children ages 6 months – 23 months
  - People age 65 or older
  - Healthy adults ages 18 – 64
  - People ages 2 – 64 with chronic illnesses
  - Healthcare workers under age 65
  - Don't know
- (10) The ability of flu vaccine to protect a person (its effectiveness) depends on:
- The health status of the person getting the vaccine
  - The age of the person getting the vaccine
  - The similarity or “match” between the vaccine and the virus
  - All of the above
  - None of the above
  - Don't know
- (11) About how long would it take to produce a flu vaccine after the virus causing a pandemic is identified?
- 2 weeks
  - 2 months
  - 6 months
  - 2 years
  - Don't know
- (12) In the past, pandemic influenza has occurred approximately every:
- 10 years
  - 15 years
  - 30 years
  - 50 years
  - Don't know
- (13) What causes a flu pandemic?
- Poor hand washing
  - No one really knows what causes flu pandemics
  - The flu virus changes so much that nobody has any immunity to it
  - People become complacent and don't get annual flu shots
  - Don't know

**Attachment L: Evaluation—Methods and Results (continued)**

- (14) When was the last flu pandemic in the United States?
- 1900
  - 1917
  - 1968
  - 1985
  - Don't know
- (15) The highly pathogenic (causing severe illness or death) avian influenza virus now found in Southeast Asia is:
- Type B virus
  - The H9N2 virus
  - The H5N1 virus
  - None of the above
  - Don't know
- (16) Which of the following best distinguishes a pandemic from an epidemic?
- A pandemic typically starts in a number of different locations, while an epidemic usually starts only in a single location.
  - A pandemic involves a disease outbreak that is international in scope, while an epidemic involves the spread of disease through a smaller region.
  - A pandemic occurs when an infectious disease starts in an animal; epidemics start only in humans.
  - A pandemic involves a disease for which there is no definitive cure; an epidemic disease is fully treatable.
  - Don't know
- (17) If there were a worldwide outbreak of flu, what percentage of the U.S. population could be vaccinated each week?
- 1% (a small number) of the U.S. population could be vaccinated each week
  - 25% (one-fourth) of the U.S. population could be vaccinated each week
  - 50% (half) of the U.S. population could be vaccinated each week
  - 100% (all) of the U.S. population could be vaccinated each week
  - Don't know

**Attachment L: Evaluation–Methods and Results (continued)**

- (18) About how many people could become ill with the flu in a moderately severe pandemic in the United States?
- Between 43 million and 100 million people will become ill
  - Between 5 million and 10 million people will become ill
  - Between 500,000 and 1 million people will become ill
  - Between 100,000 and 250,000 people will become ill
  - Don't know
- (19) About how many people could die in the United States from the flu if a pandemic occurred?
- 10,000
  - 100,000
  - 500,000
  - 1 million
  - Don't know

**Attachment L: Evaluation—Methods and Results (continued)**

**Section III: Questions about the Process**

**In this section, we are interested in your opinions about the discussion process in which you have been participating.**

(20) Please rate the quality, fairness and effectiveness of the discussions regarding pandemic influenza that have taken place in this process so far.

⇒ Please indicate how strongly you agree or disagree with the following statements by placing an ‘X’ in the appropriate box.

Statement	Agree Strongly	Agree Somewhat	Neither Agree nor Disagree	Disagree Somewhat	Disagree Strongly
I think this process has produced credible, relevant and independent information.					
This discussion was fair to all participants.					
I think this process helped me better understand the types of trade-offs involved in setting priorities for influenza vaccination.					
I think this process will increase the public’s support of the decision ultimately made on how to prioritize influenza vaccination.					
Important points were left out of our discussion.					
I think officials will use our input in their decisions about how to prioritize influenza vaccination.					
I felt comfortable talking in this discussion.					
I think this process produced a valuable outcome regarding how to prioritize influenza vaccination.					
I think other people in this discussion felt comfortable talking.					
I think I have enough information right now to have a well-informed opinion about making the best use of limited supplies of vaccine in a pandemic.					
One person or a small group of people dominated the discussion.					

Additional comments: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Attachment L: Evaluation–Methods and Results (continued)**

**Section IV: Questions about You**

**Now we need some information about you. Please remember that the information you provide in this survey is anonymous.**

(21) What is your gender?

- Male
- Female

(22) What is the highest grade of school you have completed?

- Less than high school
- Some high school
- High school graduate
- Trade or technical school
- Some college
- College graduate
- Graduate school

(23) In which of the following categories is your age?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65 or older

(24) What is your race or ethnicity?

- Hispanic
- Non-Hispanic White (Caucasian)
- African American
- Asian
- Native American
- Other [PLEASE SPECIFY] \_\_\_\_\_







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