

# 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

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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.

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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.