

The Public Engagement Project on Community Control Measures for Pandemic Influenza

Findings and Recommendations
from Citizen and Stakeholder
Deliberation Days

May 2007



Participating Organizations:

Association of State and Territorial Health Officials (ASTHO)
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Center for Biopreparedness Education-Omaha
Centers for Disease Control & Prevention (CDC)
F.O.C.U.S. (Forging Our Community's United Strength) Greater Syracuse
Georgia Department of Human Resources-Division of Public Health
Infectious Disease Society of America
National Association of County & City Health Officials (NACCHO)
Nebraska Health & Human Services System
New York State Department of Health
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Executive Summary

Background and Methods

The Public Engagement Project On Community Control Measures for Pandemic Influenza was carried out in October and November 2006 to engage the public in discussions and deliberations about the economic and social tradeoffs associated with community control measures to slow the spread of the disease. The project was sponsored by the Association of State and Territorial Health Officials (ASTHO) and The Keystone Center, serving as a third party neutral facilitator. Fourteen other organizations participated, including the Centers for Disease Control and Prevention (CDC). To conduct this public engagement, the sponsors made use of the Policy Analysis Collaborative (PACE), an innovative model for engaging both the organized stakeholder public and the general public made up of citizens-at-large (see <http://www.keystone.org/spp/health-pandemic.html>).

“When big things are at stake, the danger of error is great. Therefore, many should discuss and clarify the matter together so the correct way may be found.”

-Prince Shotoku,
574-622AD, a regent and
politician of the Imperial
Court of Japan

Two to three representatives from the organized stakeholder public were chosen from approximately ten major sectors likely to be affected by the control measures (e.g. education sector), to form a 50 member national level panel. To outreach to the larger public, a sample of approximately 260 citizens from the general public representative by age, race, and sex were recruited from each of the four principal geographic regions of the United States and included citizens in Seattle, Washington; Syracuse, New York; Lincoln, Nebraska; and Atlanta, Georgia.

The group processes were structured to provide essential information to the participants, to encourage the diverse participants to engage in discussions with each other in small groups, to weigh tradeoffs, and to reach a collective viewpoint on whether or not U.S. jurisdictions should implement a package of five community level control measures (see table 2, page 13). In addition, participants were asked to identify the anticipated challenges in implementing such control measures, and what solutions might be possible for these challenges.

Results on Control Measures

Both citizens-at-large and stakeholder representatives from affected sectors of the population expressed a high level of support for the five individual elements of the proposed package of control measures and for the package of five taken as a whole. The levels of support in both groups were nearly identical. Thus, 95% or more of the citizens and stakeholders supported encouraging sick persons to stay at home, and the same high percentage supported canceling large public gatherings and altering work patterns to keep people apart. A lower percentage of approximately four out of five citizens and stakeholders (83-84%), supported encouraging the non-ill contacts of sick persons to stay at home and a similar percentage favored closing schools and large day care facilities for an extended period. Overall, approximately two thirds of both citizens and stakeholders (64-70%) supported all five control measures.

Furthermore, citizens and stakeholders supported early implementation of the package of control measures with nearly half (44-48%) supporting implementation when pandemic influenza first strikes the U.S., and approximately one third of the public supporting implementation when influenza first strikes in their state. A relatively low percentage of citizens (4-15%) wanted to wait until influenza first strikes their community before beginning to implement control measures.

Recommendations on Implementation of Control Measures

The public identified four major categories of challenges associated with implementation of the proposed control measures and they developed thirteen priority recommendations for addressing these challenges.

The four most important challenges to emerge as themes are:

- 1) the soundness of the planning,
- 2) the economic impacts on the population,
- 3) the information needs of the population, and
- 4) the social stresses that will be created.

The thirteen priority recommendations associated with these four categories of challenges are presented below. A short paragraph elucidating each recommendation can be found in Chapter 3, Results, on page 15.

Planning & Preparation

1. Engage different levels of government and all key sectors of the community in the development of a detailed and fully-coordinated plan.
2. Conduct the planning work in the most transparent and highly visible ways possible to build public trust.
3. Conduct needs assessments to measure and track “pandemic wellness” or “pandemic readiness” scores for both individuals and communities.
4. Create incentives for employers to conduct business “continuity of operations” plans and communicate effectively what employers will expect from their employees and what supports employers will make available to lessen the burdens of the pandemic on employees.
5. Train elected officials for the leadership roles they are unfamiliar with now but will have to fulfill in a pandemic emergency.
6. Develop special focused plans for maintaining the personnel and infrastructure that will be needed to meet surge in demand for health care and the disruption of critical community services.
7. Develop clear and useful guidance for making ethical decisions around the use of scarce resources and other difficult value-laden choices in a severe pandemic.

Economic Solutions

8. Modify workplace policies or create new programs to relax the requirements on employees and to make it easier for them to bear the financial and family care burdens of the pandemic.

Information Solutions

9. Conduct an ongoing public education campaign before the pandemic strikes which provides necessary and straightforward information about the control measures, pandemic influenza, and preparedness.
10. Create messages prior to and during the pandemic that motivate individuals to comply with control measures and reinforce the expectation that compliance is a socially desirable and necessary behavior with positive benefits for all.
11. Establish specific mechanisms at the federal, state, and local levels for “just in time” communication when the pandemic arrives.

Social Solutions

12. Connect existing community organizations and volunteer groups into social networks that can deliver information, services, and social or psychological support needed to weather the pandemic.
13. Link providers in the social networks in advance of the pandemic with the people in need, paying particular attention to the most vulnerable populations.

Summary and Conclusions

The Public Engagement Project on Community Control Measures for Pandemic Influenza explicitly or implicitly asked citizens and stakeholders three questions:

- 1) Should it be done? 2) Can it be done? 3) Will it be done?

The first two questions were answered rather quickly in the affirmative—control measures should be implemented and can be implemented. There was a high level of support for the control measures and citizens and stakeholders were able to think of a number of possibly effective and practical solutions to assure successful implementation or to mitigate against their socially disruptive effects. The stakeholders worked through all of these ideas and their results were distilled into thirteen priority recommendations in four categories of challenges which must be addressed.

Failure to implement these recommendations risks failure to mobilize the necessary people and resources when and where needed at the time of the actual pandemic, failure of citizens to comply with the recommendations, failure of citizens to understand what they need to do, and a missed opportunity to reduce the social harms caused by the control measures. Thus, these recommendations provide guidance to decision-makers in preparing federal recommendations on these topics and they provide a good beginning for the creation of multi-level and multi-sector “Coordinated Action Plans” for early protection against pandemic influenza.

While the question of “will it be done” was not asked explicitly of the participants and they were not canvassed about prospects for success or failure in implementation, there was not a clear conviction on the part of the participants that control measures would actually be carried out successfully. To the contrary, participants exhibited uncertainty, and in some quarters distrust, of the government’s capacity to effectively execute the necessary actions.

“I was delighted to be a part of it and it is something that I hold dear.”

-Participant, as quoted in the Project Evaluation Report (Appendix B)

According to some participants, The Public Engagement Project on Community Control Measures for Pandemic Influenza may itself have served as a trust-building exercise for the small number of citizens who participated. Greater use of this model or other such participatory and transparent group process mechanisms may be needed to assure both the soundness and the implementation of plans to slow the spread of pandemic influenza (see http://www.upmc-biosecurity.org/website/focus/community_engage/2007_working_group/full_report.html, “Community Engagement: Leadership Tools for Catastrophic Health Events”).

A full evaluation of the project by the independent University of Nebraska Public Policy Center, titled “Evaluation of the Public Engagement Project on Community Control Measures for Pandemic Influenza,” is included in this report as Appendix B. The report concluded that the project met its 9 major goals listed below:

- Goal 1: Attract citizens to participate in the public meetings in four locations: Georgia, Washington, New York, and Nebraska.
- Goal 2: Recruit participants with diverse perspectives and demographic characteristics such as age, gender, race/ethnicity, education, and income.
- Goal 3: Understand what motivated citizens to participate in the process.
- Goal 4: Provide information to participants so they have sufficient knowledge about pandemic influenza to adequately consider and discuss community control measures.
- Goal 5: The process results in a balanced, honest, and reasoned discussion of the issues while respecting diversity of views.
- Goal 6: Citizens and stakeholders deliberate and consider multiple points of view and the process affects the opinions and judgments of participants related to values and implementation of community control measures.
- Goal 7: Citizens contribute useful information for the stakeholder deliberations, and stakeholders considered and integrated citizen input into their recommendations.
- Goal 8: Citizens and stakeholders are satisfied with the process and believe their input will be considered by decision-makers.
- Goal 9: Citizen and stakeholder input receives serious consideration by decision-makers and adds value to the input already being received from expert groups.

Chapter 1: Background

Background

The difficult decisions about the nature and timing of community control measures after the appearance of pandemic influenza led the Coordinating Center for Infectious Diseases and the Office of the Director at the Centers for Disease Control and Prevention (CDC) to call for a public consultation on the issue. As a result, CDC signed a cooperative agreement in 2006 with the Association of State and Territorial Health Officials (ASTHO), to engage the citizen and stakeholder publics.

The main goals of the project, entitled the “Public Engagement Project on Community Control Measures for Pandemic Influenza,” were to learn what level of support the public might have and what tradeoffs citizens might be willing to make for a package of control measures that would be socially disruptive but have the potential to slow the spread of disease (see table 2, page 13). The Public Engagement Project ultimately enlisted the collaboration of 16 participating organizations, and ASTHO contracted with The Keystone Center in the fall of 2006 to assist with implementation of the project.

“People will be more willing to comply [with social control measures] if they feel like they have been heard, and if they also feel that the people who make policies have an understanding of where the average citizen might be.”

-Participant, as quoted in the Project Evaluation Report (Appendix B)

“I really felt like the process was one of the best facilitated processes that I have participated in a very long time.”

“It kind of reminded me of the jury system – that although you think sometimes that the public doesn’t get it, if you give them the right information they really do get it and make reasonable decisions based on the information given.”

-Participants, as quoted in the Project Evaluation Report (Appendix B)

The design of the project was modeled after the Public Engagement Pilot Project on Pandemic Influenza (PEPPPI), conducted in 2005, on the question of who should be vaccinated first in the early days of an influenza pandemic when vaccine supplies are still limited. This model seeks to recruit approximately 100 citizens-at-large from the four major regions of the United States and a separate panel of representatives from organizations most affected by the policy decisions (stakeholders). The citizens-at-large produced their perspective on the question of interest and the panel of stakeholders met at the end of the citizen deliberations to integrate the findings from these deliberations and to produce a final report reflecting the best thinking of both groups and the “societal perspective” on the question of interest.

Chapter 2: Methods for Citizen and Stakeholder Deliberations

Methods for Citizen Deliberations

In each city, citizens heard presentations from subject matter experts from CDC or from the local health departments about the essential information they needed to have an informed discussion about community control measures for influenza. Multiple experts were on hand and answered numerous questions from the audience both immediately after the presentations and throughout the day during the deliberations.

To frame their deliberations, citizens were given a hypothetical scenario describing how an influenza pandemic might unfold in the U.S., including assumptions about the severity of the pandemic, the efficacy of control measures, and possible negative consequences caused by the control measures.

The citizens accomplished five tasks:

1. learned the facts essential to have an informed discussion about pandemic influenza and proposed community control measures;
2. discussed the pros and cons of five proposed control measures;
3. decided if they supported implementation of these measures, and if so, when;
4. identified the most important concerns surrounding implementation; and
5. proposed actions that could assure successful implementation.

To accomplish these deliberative tasks, citizens participated in small group facilitated discussions of about 10 persons each and in two large group sessions with all participants to review the challenges and to discuss possible solutions. Voting on the control measures was carried out by electronic devices which produced instantaneous results for the participants and organizers. These results were then discussed and further refined.



Methods for Stakeholder Deliberations

Several representatives from the following sectors were invited to participate in a two-day meeting on November 29-30, 2006. Approximately 50 representatives from organizations that would be affected directly by a severe pandemic attended the meeting and participated in the deliberations. Among the sectors included were health professional organizations, federal agencies, state and local government organizations, business, education, faith community, minority organizations, consumer advocates, and labor sectors.

Participants heard a presentation on the basic information they needed to obtain to have an informed discussion. There were several subject matter experts in attendance who were able to answer questions.

The participating stakeholders heard the results from the four citizen meetings described above. In addition, citizen representatives from each of the participating cities were present at the stakeholder meeting and gave their perspectives on the deliberations in their city. In addition, the results of a nationwide poll conducted by the Harvard School of Public Health were presented.

The stakeholders were given the same five tasks assigned to citizens (as described on page 8) but with the additional tasks of integrating the results of the citizen deliberations into their discussions, and of identifying which proposed actions were considered the most important to carry out. More specifically, the stakeholders were asked to identify those actions “without which the implementation of pandemic influenza control measures would fail.”

“I believe it is our civic responsibility when asked by governmental agencies for feedback to provide as much opinion as possible. I saw it as an opportunity to influence public policy and to make sure the priorities of me and the people that we know are taken into account when public policy is being set.”

-Participant, as quoted in the Project Evaluation Report (Appendix B)

“I was satisfied in a personal sense that I got to help put my fingerprint, however faint it might be...my thoughts on what might be federal guidelines and I think that’s pretty important.”

-Participant, as quoted in the Project Evaluation Report (Appendix B)

To accomplish these tasks, the stakeholders participated in four small group discussions organized around each of four categories of challenges previously identified by the citizens. They prioritized the actions proposed in the small group discussions and reconvened in a large group to present their results. On day two, the stakeholders participated in one large group discussion to further clarify and elaborate on the key actions proposed on day one. The ideas put forward were captured by staff from The Keystone Center, and a final list of recommendations has been distilled from The Keystone report. On day two, stakeholders also voted electronically on a series of questions designed to evaluate their level of support for the proposed control measures.

Chapter 3: Results

Section A: On Control Measures

#1: Numbers and Demographics

An estimated total of 259 citizens-at-large from diverse age, sex, and ethnic groups from the four parts of the United States met in Atlanta, Georgia; Lincoln, Nebraska; Seattle, Washington; and Syracuse, New York; for four full deliberation-days on October 28, 2006, November 4, 2006, and November 18, 2006.

Participants represented 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, education, and income.

Table 1 compares the demographic characteristic from the four citizen meetings to the demographics of the broader population in the four communities. Participants in the four meetings were over-representative of the 45 – 65 age categories and under-representative of the younger age categories (18 – 34). Females were over-represented in comparison to community demographics. Whites and Native American participants were over-represented while Blacks, Asians, and Other Race/Ethnicity were under-represented. Hispanics participated in about the same proportion as the general population of the four communities.

Participants in the four meetings had higher levels of education than the general populations of those communities. The percentage of participants with graduate degrees was over six times higher than the general population. Individuals with no college experience were substantially under-represented at the meetings. Individuals with higher incomes were over-represented at the meetings. The percentage of meeting participants with annual household incomes of \$100,000 or more was more than twice as high as the general population, and the percentage of participants with annual household incomes of \$30,000 or less was about half of the percentage of the population in the four communities.



Table 1
Comparison of Participant Demographics
to Community Demographics

| | | Meeting Participants | Community Demographics |
|-----------------|--------------------------|----------------------|------------------------|
| Age | 18-24 | 6.5% | 10.5% |
| | 25-34 | 8.0% | 18.0% |
| | 35-44 | 17.6% | 15.2% |
| | 45-54 | 31.2% | 12.5% |
| | 55-64 | 28.1% | 7.0% |
| | 65+ | 8.5% | 11.3% |
| Gender | Male | 35.7% | 49.1% |
| | Female | 64.3% | 50.9% |
| Race/ Ethnicity | Hispanic White | 4.0% | 4.7% |
| | Hispanic Black | 0.5% | |
| | White | 74.7% | 62.4% |
| | Black | 12.6% | 25.4% |
| | Asian | 3.0% | 5.4% |
| | Native American | 1.5% | 0.8% |
| | Other | 3.5% | 5.1% |
| Education | Less than high school | 0% | 5.4% |
| | Some high school | 0.5% | 11.4% |
| | High school graduate | 4.5% | 22.8% |
| | Some college | 22.1% | 19.4% |
| | College graduate | 29.1% | 27.8% |
| | Some graduate school | 9.5% | 13.3% |
| | Graduate school graduate | 34.2% | 5.4% |
| Income | \$15,000 or less | 8.2% | 21.2% |
| | \$15,001 - \$30,000 | 8.8% | 14.4% |
| | \$30,001 - \$60,000 | 29.4% | 28.3% |
| | \$60,001 - \$100,000 | 27.8% | 25.0% |
| | \$100,001 or more | 25.8% | 11.2% |

An estimated total of fifty stakeholders attended the two day meeting on November 29-30, 2006. Representatives from all of the major affected sectors were present, and in many cases, the individuals in attendance were experienced professionals within their organizations. Many questions which came up during the deliberations could be answered quickly and authoritatively because the persons in attendance had the information necessary to respond. There was good minority group representation at the meeting. A list of the diverse stakeholder representatives is included as Appendix A in this report.

A full evaluation of the project by the independent University of Nebraska Public Policy Center, titled “Evaluation of the Public Engagement Project on Community Control Measures for Pandemic Influenza,” is included in this report as Appendix B.

#2: Level of Support for Control Measures

Participants considered two control measures to be the least challenging (Table 2). Thus, all or nearly all of the participants indicated they supported implementation of control measures to keep sick persons at home and to make changes in work patterns and schedules. Support for canceling large public gatherings was also very high in three of the four cities (99-100%) but was only 79% in Seattle. The reasons for the lower level of support in Seattle are unknown. Stakeholders shared with citizens a high level of support for the same three measures discussed above.

“*I believe strongly that our government is of the people, for the people, and by the people, so I really believe that the opportunity for the people to speak should be given a good deal of weight to governmental deliberations. This is one of the chances where we as a people, as a representative of the people, really get a chance to talk back to the government.*”

-Participant, as quoted in the Project Evaluation Report (Appendix B)

Two control measures were deemed the most challenging. In three of the four locations, approximately one out of five participants did not support encouraging the non-ill household contacts of sick persons to stay at home, and an equal percentage did not support school closings. In contrast, support for these two measures was very high in Nebraska (92-100%). The reasons for the higher level of support, not only for these two measures but for all five measures in Nebraska, are unknown. However, one of the meeting organizers noted that “the eastern Nebraska area is fairly well educated and educable on this issue because they are in the bull’s eye of tornadoes every summer and know how to prepare. They are also the friendliest people you’ll meet anywhere, and they truly work together in communities. Personal responsibility is strongly valued, but community support is a given.”

Stakeholders agreed with citizens who found school closures and keeping non-ill contacts at home the most challenging control measures. In fact, the average level of support for these two measures was virtually identical in the two groups at 83-84%.

Implementation of all five control measures in combination was supported by two-thirds of the participants in Atlanta and Syracuse, and by 96% in Nebraska. However, only 30% of participants in Seattle supported all five measures (see discussion in next section). The average level of support for all five measures by citizens (64%) was similar to the level of support for all five measures among stakeholders (70%).

| Table 2 Percentages of Citizens and Stakeholders who Supported Individual or Combined Control Measures | | | | | | |
|---|---------|---------|---------|----------|----------------------|--------------|
| Control Measures | Atlanta | Seattle | Lincoln | Syracuse | Average for Citizens | Stakeholders |
| | N=84 | N=66 | N=34 | N=75 | N=259 | N=50 |
| 1. Encouraging sick persons to stay at home | 100% | 96% | 100% | 100% | 99% | 100% |
| 2. Encouraging non-ill contacts to stay at home | 82% | 77% | 92% | 82% | 83% | 83% |
| 3. Canceling large public gatherings | 100% | 79% | 100% | 99% | 95% | 100% |
| 4. Closing schools and large day care facilities | 78% | 78% | 96% | 82% | 84% | 83% |
| 5. Altering work patterns | 95% | 93% | 96% | 96% | 96% | 96% |
| | | | | | | |
| All Five | 67% | 30% | 96% | 63% | 64% | 70% |
| Some | 32% | 61% | 4% | 37% | 33% | 30% |
| None | 1% | 9% | 0% | 0% | 3% | 0% |
| | | | | | | |

#3: Timing of Implementation of Control Measures

Because the assumption in the scenario was one in which the disease was still outside the U.S., a separate question was added in three of the four cities after the first meeting to ascertain more carefully exactly when citizens might support implementation of the control measures (see Table 3, page 14). The citizens were asked if they supported implementation at the following times:

- 1) at no time;
- 2) when the disease is still outside the U.S.;
- 3) when the disease first strikes the U.S.;
- 4) when the disease first strikes your state (only Syracuse and Lincoln);
- 5) when the disease first strikes your region or area of the state (only Syracuse);
- 6) when the disease first strikes your community; and
- 7) when many persons are sick in your community.

Table 3

Percentages of Citizens and Stakeholders who Supported Control Measures at Various Times in the Pandemic

| Timing of Control Measures | Atlanta | Seattle | Lincoln | Syracuse | Average for Citizens | Stakeholders |
|-------------------------------------|---------|---------|---------|----------|----------------------|--------------|
| | N=84 | N=66 | N=34 | N=75 | N=259 | N=50 |
| When Still Outside US | NA | 25% | 25% | 17% | 22% | 17% |
| First Strikes US | NA | 45% | 58% | 29% | 44% | 48% |
| First Strikes State | NA | NA | NA | 32% | 32% | 30% |
| First Strikes Region of your state | NA | NA | NA | 22% | 22% | NA |
| First Strikes your community | NA | 27% | 17% | 0% | 15% | 4% |
| Many persons sick in your community | NA | 2% | 0% | 0% | 0% | 0% |
| At no time | NA | 2% | 0% | 0% | 0% | 0% |

The highest percentage of citizens in both Seattle and Lincoln supported implementation of the control measures when the disease first strikes the U.S. This is perhaps earlier than experts might have expected in labeling the control measures as “community” control measures since it suggests citizens could support “national” or “state” control measures. Citizens in Syracuse answered “when the disease first strikes their state,” however these citizens also appeared more willing to support implementation when the disease first strikes the U.S. after they were reminded in response to questions that infected persons can be contagious before they are symptomatic and that disease can spread rapidly with air travel.

Thus, from all three cities where the question about the timing of implementation was asked very explicitly, citizens supported early implementation of control measures—even before the disease affects their particular community. As stated by a Syracuse participant, citizens expect the health authorities to tell them when to actually “pull the trigger” on implementation with the understanding that it includes all five measures at once. However, what the citizens made clear is their support for implementation early enough to prevent disease. As the same citizen expressed it, “it is better to act early (err on the side of caution) than to wait too long and have the disease already well established in the community.”

Stakeholders voted on when to implement control measures and the highest percentage (48%) voted for “when pandemic influenza first strikes the U.S.,” followed by “when it first strikes your state” (30%). Only small percentages supported control measures when the disease is still outside the U.S. or after the disease has already reached a community.

Thus, both citizens and stakeholders support early implementation of control measures, well before it arrives in a particular community.

Section B: Recommendations on Implementation

Numerous challenges/concerns and possible solutions/recommendations were identified during the public dialogues with citizens and stakeholders. The themes which emerged can be interpreted as the most important challenges to implementation, and recommendations were grouped accordingly in the same categories. The themes were developed by grouping similar comments found in the notes of discussion facilitators, report-outs, and large group plenary sessions. At the final meeting, participants were asked to identify the most important solutions without which implementation of community control measures would fail. There are 13 priority recommendations that were distilled from these deliberations. This report presents the challenges and recommendations in general terms rather than linking specific concerns to specific control measures since the five control measures against a severe pandemic are being proposed as a package or a combined set of actions.

The four most important challenges to emerge as themes are:

- 1) the soundness of the planning;
- 2) the economic impacts on the population;
- 3) the information needs of the population; and
- 4) the social stresses that will be created.

“This was a great opportunity to make use of concerned citizens in a meaningful and structured way.”

The thirteen priority recommendations associated with these four categories of challenges are followed by a short paragraph elucidating each recommendation.

-Participant, as quoted in the Project Evaluation Report (Appendix B)

Planning & Preparation

1. **Engage different levels of government and all key sectors of the community in the development of a detailed and fully-coordinated plan.**

Both the stakeholders and community members expressed a deep concern over the current lack of coordination between and among private and public sectors. Creating multi-level and multi-player networks of government officials and organizations, educators, businesses, health care groups, faith-based communities, media, and citizens to develop a decision-making structure and to collaborate on planning was judged essential for success. Creation of these networks should first involve a detailed study of current collaborative arrangements and also be federally funded.

2. **Conduct the planning work in the most transparent and highly visible ways possible to build public trust.**

Stakeholders and citizens expressed a lack of confidence that responsible parties would complete the planning necessary for the control measures to be effective. This is both a matter of distrust and a skepticism about the competence of responsible persons to accomplish the needed tasks. The memory of the problems associated with Hurricane Katrina has not faded. By keeping as much planning as possible transparent, and by bringing visibility to planning efforts, trust could be gained and confidence established over time. Suggestions for these types of activities included having one credible national spokesperson and a high visibility event like a White House summit.

| CHALLENGES | Thirteen Priority Recommendations |
|-------------------------------|---|
| The Soundness of the Planning | 1. Engage different levels of government and all key sectors of the community in the development of a detailed and fully-coordinated plan. |
| | 2. Conduct the planning work in the most transparent and highly visible ways possible to build public trust. |
| | 3. Conduct needs assessments to measure and track “pandemic wellness” or “pandemic readiness” scores for both individuals and communities. |
| | 4. Create incentives for employers to conduct business “continuity of operations” plans and communicate effectively what employers will expect from their employees and what supports employers will make available to lessen the burdens of the pandemic on employees. |
| | 5. Train elected officials for the leadership roles they are unfamiliar with now but will have to fulfill in a pandemic emergency. |
| | 6. Develop special focused plans for maintaining the personnel and infrastructure that will be needed to meet the surge in demand for health care and the disruption of critical community services. |
| | 7. Develop clear and practically useful guidance for making ethical decisions around the use of scarce resources and other difficult value-laden choices that will be required in a severe pandemic. |
| Economic Impacts | 8. Modify workplace policies or create new programs to relax the requirements on employees and to make it easier for them to bear the financial and family care burdens of the pandemic. |
| Information Needs | 9. Conduct an ongoing public education campaign before the pandemic strikes which provides necessary and straightforward information about the control measures, pandemic influenza, and preparedness. |
| | 10. Create messages prior to and during the pandemic that motivate individuals to comply with control measures and reinforce the expectation that compliance is a socially desirable and necessary behavior with positive benefits for all. |
| | 11. Establish specific mechanisms at the federal, state, and local levels for “just in time” communication when the pandemic arrives. |
| Social Concerns | 12. Connect existing community organizations and volunteer groups into social networks that can deliver information, services, and social or psychological support needed to weather the pandemic. |
| | 13. Link providers in the social networks in advance of the pandemic with the people in need, paying particular attention to the most vulnerable populations. |

3. Conduct needs assessments to measure and track “pandemic wellness” or “pandemic readiness” scores for both individuals and communities.

Stakeholders and citizens expressed concern that individuals and communities would not be prepared for a pandemic. In order to identify planning needs, the stakeholders suggested creating and administering needs assessments in local communities. These assessments would help individuals and communities determine their “pandemic wellness score” by identifying how prepared they are for a pandemic. The assessments could be disseminated through schools, employers, agencies, and faith-based organizations.

4. **Create incentives for employers to conduct business “continuity of operations” plans and communicate effectively what employers will expect from their employees and what supports employers will make available to lessen the burdens of the pandemic on employees.**
Stakeholder and citizens were concerned that individuals may not comply with many of the measures because the current climate of business does not support absenteeism, leave, and flexibility. Since they have not heard specifics about how these issues will be handled by their business, most employees are unsure how their place of employment would react if they took leave, stayed home, or wanted to work from home. Stakeholders suggested creating federal incentives to encourage businesses to plan immediately and create “supportive pandemic workplace policies” for benefits, illness and liberal leave and flexible work arrangements. These “continuity of operations” plans should then be clearly communicated to employees.
5. **Train elected officials for the leadership roles they are unfamiliar with now but will have to fulfill in a pandemic emergency.**
Stakeholder and citizens expressed concern that elected officials, especially on the local level, would be ill prepared to assume the leadership roles required by a pandemic. Stakeholders suggested preparing officials now by creating “just in time” training. This training would make leaders aware of their role and responsibilities in the implementation process. It would also help prepare them to communicate effectively with the public by designating pathways to ensure clear messages and feedback loops.
6. **Develop special focused plans for maintaining the personnel and infrastructure that will be needed to meet surge in demand for health care and the disruption of critical community services.**
Both stakeholders and citizens were worried about how needed supplies and services would be maintained in a pandemic. First among these concerns was how the health care system would deal with a surge in the face of staffing shortages caused by a lack of volunteers and parents who are health professionals staying home with children. Stakeholders suggested creating a network that includes additional staff and facilities to provide critical care. Those displaced by the pandemic such as teachers would be retrained to act as staff and buildings that are closed or would not be used at that time such as schools and day cares would act as critical care facilities. To maintain other essential services and supplies, stakeholders suggested that businesses need to identify critical infrastructure employees and support them with in-home childcare and senior care services. They also need to plan for other critical elements they will need to maintain regular operations during a pandemic.
7. **Develop clear and practically useful guidance for making ethical decisions around the use of scarce resources and other difficult value-laden choices in a severe pandemic.**
Stakeholders were particularly concerned over how decisions would be made regarding the distribution of scarce life saving resources such as anti-viral medication, respirators, vaccination (when available), hospital beds, and masks as well as other scarce resources such as food, water, and funeral services. They suggested creating ethical decision-making guidance through a detailed process that begins with the federal funding of community-level conversations and deliberations on these topics. A work group would take the findings of the conversations and develop ethical guidelines to determine how scarce community resources would be dispensed.

Economic Solutions

8. **Modify workplace policies or create new programs to relax the requirements on employees and to make it easier for them to bear the financial and family care burdens of the pandemic.**

Stakeholder and citizens were concerned that the economic impact on individual workers may be a key driver to compliance. In order to mitigate the economic impacts on the workforce, the stakeholders suggested making current programs such as Food Stamps, 401K, Family Medical Leave Act (FMLA), Medicaid, and unemployment adaptable to pandemic conditions. They also suggested the creation of a new “Pandemic Leave” policy. This law would address the leave issues associated with a pandemic such as absence from work due to the illness of self or family or due to school closure. It would protect workers from being fired due to such absences. It might also allow for business interruption insurance.

Information Solutions

9. **Conduct an ongoing public education campaign before the pandemic strikes which provides necessary and straightforward information about the control measures, pandemic influenza, and preparedness.**

Stakeholders and citizens were concerned about the lack of information that individuals currently have about pandemic influenza. In order to educate people on the situation, stakeholders suggested developing a comprehensive campaign. They suggested creating a communication tree with the base of the message centralized and key messengers such as educators, health care, social services, labor unions, clergy, rappers, and employers identified for different sectors of the population. These messengers would be responsible for disseminating information in the workplace, schools, hospitals, service agencies, union meetings, and religious meetings. In general, messages should be memorable by using icons and symbols and catchy phrasing like “10 things to know, 10 things to do.” Traditional media should be used such as the web, posters, and pamphlets as well as nontraditional media such as iPods, television shows, and Hollywood and educational movies.

10. **Create messages prior to and during the pandemic that motivate individuals to comply with control measures and reinforce the expectation that compliance is a socially desirable and necessary behavior with positive benefits for all.**

Stakeholders and citizens were concerned that individuals may not be motivated to comply for a variety of reasons such as feeling a lack of urgency, placing individual responsibility before the good of society, and concern over stigmatization. In order to motivate people, citizens suggested shifting perceptions from focusing on the burdens of compliance to the “greater good” of compliance. Such a change in cultural thinking would be facilitated through messages that make compliance socially acceptable and emphasize the benefits of complying. Messages may also subtly draw on personal responsibility, collective responsibility and advance planning.

11. Establish specific mechanisms at the federal, state, and local levels for “just in time” communication when the pandemic arrives.

Stakeholders and citizens were concerned that during a pandemic, messages would be fragmented, inconsistent, and sporadic. Stakeholders stressed that the government must “be first, be right, [and] be credible.” They suggested creating a “just in time” infrastructure for communication in order to ensure clear and accurate messages. First, current emergency communication information structures should be considered and assessed. Next, planners could enhance current structure where necessary with the pre-pandemic information tree communication to create a solid channel of clear and consistent messaging.

Social Solutions

12. Connect existing community organizations and volunteer groups into social networks that can deliver information, services, and social or psychological support needed to weather the pandemic.

Stakeholders and citizens were concerned that many needs such as information, bereavement services, and counseling might arise during a pandemic and overburden already strapped nonprofit groups. The stakeholders stressed “do not reinvent the wheel.” They suggested drawing on established relationships to create a local social network of organizations and volunteer groups that could work together to fulfill these needs. This network could create a “menu” of resources, conduct a needs assessment, and create a program that would outline how needs would be met.

13. Link providers in the social networks in advance of the pandemic with the people in need, paying particular attention to the most vulnerable populations.

Stakeholders and citizens were concerned that individuals, especially those from disadvantaged populations such as migrant workers, the homeless, prisoners, and illegal immigrants would not get the basic supplies needed during a pandemic. Stakeholders suggested creating a network responsible for using the needs assessments to identify those in need and then to link individuals to providers who can fulfill those needs.



Chapter 4: Summary and Conclusions from the Overall Project

The Public Engagement Project on Community Control Measures for Pandemic Influenza explicitly or implicitly asked citizens and stakeholders three questions:

1) Should it be done? 2) Can it be done? 3) Will it be done?

The first two questions were answered rather quickly in the affirmative—control measures should be implemented and can be implemented. There was a high level of support for the control measures and citizens and stakeholders were able to think of a number of possibly effective and practical solutions to assure successful implementation or to mitigate against their socially disruptive effects. The stakeholders worked through all of these ideas and their results were distilled into thirteen priority recommendations in four categories of challenges which must be addressed.

“Just by having a seat at the table and having a voice, we felt very empowered – all of us. This is going to spur all of us to become much more active.”

-Participant, as quoted in the Project Evaluation Report (Appendix B)

Failure to implement these recommendations risks failure to mobilize the necessary people and resources when and where needed at the time of the actual pandemic, failure of citizens to comply with the recommendations, failure of citizens to understand what they need to do, and a missed opportunity to reduce the social harms caused by the control measures. Thus, these recommendations provide guidance to decision-makers in preparing federal recommendations on these topics and they provide a good beginning for the creation of multi-level and multi-sector “Coordinated Action Plans” for early protection against pandemic influenza.

While the question of “will it be done” was not asked explicitly of the participants and they were not canvassed about prospects for success or failure in implementation, there was not a clear conviction on the part of the participants that control measures would actually be carried out successfully. In fact, participants exhibited uncertainty, and in some quarters distrust, of the government’s capacity to effectively execute the necessary actions.

According to some participants, The Public Engagement Project on Community Control Measures for Pandemic Influenza may itself have served as a trust-building exercise for the small number of citizens who participated. Greater use of this model or other such participatory and transparent group process mechanisms may be needed to assure both the soundness and the implementation of plans to slow the spread of pandemic influenza.



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Appendix B:

Evaluation of the Public Engagement Project on Community Control Measures for Pandemic Influenza

March 23, 2007



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Evaluation Summary

The Public Engagement Project on Community Control Measures for Pandemic Influenza was conducted in November 2006 to engage citizens and stakeholders in deliberations about community control measures that might be implemented in the event of an influenza pandemic. The Public Engagement Project included one-day citizen meetings held in four locations around the country and one two-day stakeholder meeting held in Washington D.C. The Association of State and Territorial Health Officials (ASTHO) contracted separately for an independent evaluation with the University of Nebraska Public Policy Center. The evaluation included four components: a pre-post survey completed by citizens and stakeholders, focus groups conducted with citizens immediately after each meeting, individual telephone interviews conducted with citizens and stakeholders, and a document review to assess how the public engagement process influenced policy. Below are the key findings from the evaluation for each of the project goals. Overall, the evaluators found that the project was successful in meeting these goals.

Participation and Representation

Goal 1: Attract citizens to participate in the public meetings in four locations: Georgia, Washington, New York, and Nebraska

The process was successful in attracting citizens to engage in the process. Although none of the four sites met the goal of attracting 100 citizens to participate in the deliberations, each citizen meeting included enough citizens to break out into multiple small groups and engage in dialogue as a large group. There were 259 citizens who participated in the four meetings, an average of 65 citizens per site. This level of participation was impressive since citizens gave up nearly a full Saturday to participate in each meeting, and they were not compensated for their participation.

Goal 2: Recruit participants with diverse perspectives and demographic characteristics such as age, gender, race/ethnicity, education, and income

Participating citizens represented diverse interests and demographic characteristics, although certain groups appeared to be underrepresented (e.g., low income, racial/ethnic minorities, persons with lower education levels, younger people). The goal of the public engagement process was not to attract participants in proportion to the demographic characteristics in the communities in which the meetings were held, but rather to attract enough diversity to represent a variety of perspectives and points of view. In this sense, the process was successful. Citizens participating in the meetings appeared to represent a diversity of perspectives and expressed a variety of views.

Goal 3: Understand what motivated citizens to participate in the process

Citizens were motivated to participate by a sense of civic responsibility or by a belief that their input would have an impact on public policy. Many of the participants had a personal or professional interest in pandemic influenza preparedness; some were in the health care profession or involved in health care planning, while others had a connection to high-risk groups. Most citizens indicated they had received information about the meeting through email from listservs or groups to which they belonged. This method of recruitment may have contributed to some demographic groups being under represented (e.g., persons with lower levels of education). Strategies to increase participation and diversity in future public engagement processes include providing more advanced notice of meetings, holding meetings on weekdays instead of weekends, advertising through alternative sources, and paying stipends to participants.

Knowledge of Participants and the Dialogue and Deliberation Process

Goal 4: Provide information to participants so they have sufficient knowledge about pandemic influenza to adequately consider and discuss community control measures

The presentation of information about pandemic influenza and community control measures at the meetings was successful in increasing the knowledge of citizens and stakeholders. The citizens and stakeholders had sufficient knowledge to engage in informed discussion and to weigh pros and cons regarding community control measures. Compared to citizens, stakeholders had higher levels of pandemic influenza knowledge coming into the meeting; however, citizen knowledge was closer to stakeholder knowledge by the end of the meetings. Participants believed they had adequate knowledge to engage in informed deliberations and appreciated the quality of the presentations. Many participants reported reading pandemic influenza materials before attending the meeting; it is likely the participants had higher levels of knowledge about pandemic influenza prior to the meetings than the average citizen.

Goal 5: The process results in a balanced, honest, and reasoned discussion of the issues while respecting diversity of views

Although observers noted substantial process differences across citizen meetings and across small group facilitators within each meeting, the overall public engagement process was successful in producing a high quality deliberative procedure from the perspective of the participants. Citizens generally believed that participants felt comfortable talking in the meeting; the discussion was fair to all participants; the process helped them understand the types of trade-offs involved; the process produced credible and independent information; the process was not dominated by one person or a small group of people; and no important points or perspectives were left out of the discussion. Overall, stakeholders also thought the process was of high quality, although less so than citizens. Participants generally appreciated the skill level of facilitators and indicated that organized facilitation helped focus their discussion and ensure that all participants had the opportunity to speak. There were mixed reviews about the inclusion of electronic polling as part of the process. Some found it valuable, while others thought it detracted from the process, taking time away from deliberation and discussion.

Goal 6: Citizens and stakeholders deliberate and consider multiple points of view and the process affects the opinions and judgments of participants related to values and implementation of community control measures

Participation in the meetings changed participant perspectives about social values and the acceptability and likelihood of compliance with community control measures. For citizens, social order, responsibility, utilitarianism, and equality increased in importance following the deliberation. Many of the community control measures were significantly more acceptable after the deliberations including isolating ill persons at home, canceling events where large groups of people are expected to gather, not allowing kids to congregate outside of schools and day care centers, and encouraging businesses to use alternative work locations. After the public engagement process, participants were more likely to believe that local units of government should make determinations about community control measures. These findings support the hypothesis that providing information to citizens and stakeholders engaging them in discussions about policy issues produces different results than public polling or opinion surveys.

Value of Citizen Participation and Stakeholder Input

Goal 7: Citizens contribute useful information for the stakeholder deliberations, and stakeholders considered and integrated citizen input into their recommendations

Stakeholders were impressed with the depth of thought from the citizen meetings and reported using citizen input during the stakeholder deliberations. Citizen participants in the stakeholder meeting felt included and believed their input was valued by stakeholders. Stakeholders generally believed that citizen input added legitimacy to the process and helped generate policy maker support for the recommendations.

Goal 8: Citizens and stakeholders are satisfied with the process and believe their input will be considered by decision makers

Citizens and stakeholders generally thought the input provided would be used by policymakers. Participants also believed the deliberative process would increase the public's support of the decision that would be made about community control measures. The citizen focus groups and interviews indicate most people were generally satisfied with what they thought were the outcomes of the meeting, though several people were unclear about what the actual outcomes were or how the input would be used. Participants were more inclined to believe local or state health departments should make decisions about community control measures rather than other levels of government or individuals themselves.

Goal 9: Citizen and stakeholder input receives serious consideration by decision makers and adds value to the input already being received from expert groups

At this point, it is difficult to determine what impact the public engagement process had on official policy. The process was identified as providing input to the Interim Pre-Pandemic Planning Guidance Report, along with many other stakeholders and processes. It is difficult to disentangle the impact of the public engagement results from other sources of input. Furthermore, the Pre-Pandemic Guidance Report is issued as preliminary guidance rather than final recommendations; although the report did not explicitly adopt the 13 recommendations from the public engagement process, further efforts are required to determine how policy makers use the input in future reports. The next steps in the evaluation are to conduct interviews with policy makers to determine how the input was considered and to review subsequent official documents pertaining to policies or guidance about community control measures.

Chapter 1: Introduction

This evaluation of the Public Engagement Project on Community Control Measures for Pandemic Influenza examines a mechanism for engaging the public on policy decisions about the implementation of community controls in the event of an influenza pandemic 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 January 2007. At the time of this report, all of the survey data had been collected and preliminary analyses of this data are presented; interviews with citizens and stakeholders had been conducted, and qualitative information from the interviews are included. The next step in the evaluation is to conduct an assessment of how the stakeholder input was used by decision makers.

The Public Engagement Project

This project originated from a desire by the officials from the Centers for Disease Control and Prevention, U.S. Department of Health and Human Services to obtain citizen and stakeholder input regarding possible community control measures that could be implemented in the event of pandemic influenza. The project was sponsored by the Association of State and Territorial Health Officials (ASTHO) and The Keystone Center, serving as a third party neutral facilitator. To obtain input, citizen meetings were held across the United States in cities representative of four geographic areas: Atlanta, Georgia in the south; Syracuse, New York in the northeast; Lincoln, Nebraska in the Midwest; and Seattle, Washington in the west. All citizen meetings were held in October and November 2006. A meeting for stakeholders was held in Washington, D.C. November 29 – 30, 2006. Citizens were informed about the meetings through a variety of sources, and were not paid to participate.

The citizen meetings followed a similar format: citizens were welcomed and provided an overview of the meeting; experts provided information about pandemic influenza and community control measures; citizens were given a hypothetical scenario about pandemic influenza; citizens deliberated in small groups to discuss the pros and cons of the community control measures and the challenges of implementation; citizens discussed challenges and potential solutions in the large group; and voting was conducted on each community control measure using electronic polling. The stakeholder meeting followed a similar format, although the stakeholders met for two days and were provided a presentation summarizing the citizen deliberations. A small number of citizens who had participated in the four local meetings also attended the stakeholder meeting. The input from the citizen meetings was incorporated into the stakeholder deliberations and a report was produced that included recommendations.

Program Evaluation Questions

The evaluation addresses the following questions:

1. Participation and recruitment questions:

- a. Was the process successful in attracting citizens to participate in the public meetings in four locations: Georgia, Washington, New York, and Nebraska?
- b. Was the process successful in recruiting participants with diverse perspectives and demographic characteristics such as age, gender, race/ethnicity, education, and income?
- c. What motivated citizens to participate in the process?

2. Process issues:

- d. To what extent did participants have sufficient knowledge about pandemic influenza to adequately consider and discuss community control measures for pandemic influenza?
- e. To what extent did the process result in a balanced, honest, and reasoned discussion of the issues while respecting diversity of views?
- f. To what extent did citizens and stakeholders deliberate and consider multiple points of view?
- g. To what extent did the process affect the opinions and judgments of participants related to values and implementation of community control measures?

3. Product issues:

- h. To what extent did citizens contribute useful information for the stakeholder deliberations, and did stakeholders consider and integrate citizen input into their recommendations?
- i. To what extent were citizens and stakeholders satisfied with the process and believe their input would be considered by decision makers?
- j. To what extent did citizen and stakeholder input receive serious consideration by decision makers and add 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 policy?

Chapter 2: Evaluation Methods

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 four major methodological components:

1. Pre-post surveys completed by citizens and stakeholders
2. Individual interviews conducted with stakeholders and citizens who attended the meetings
3. Focus groups conducted immediately after each of the citizen meetings
4. A document review of the Interim Pre-pandemic Planning Guidance Report issued by the Centers for Disease Control and Prevention to determine how the public engagement process is referenced. Individual interviews will be implemented in the future to determine how citizen and stakeholder input is used by decision makers.

Pre-Post Survey

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

1. Stakeholders who participated in the November meeting in Washington, D.C.
 - About 50 stakeholders participated in the Washington D.C. meeting; 17 stakeholders completed the pre-survey on November 29, 2006, and 17 stakeholders completed the post-survey on November 30, 2006.
2. Eighty-four citizens who were recruited and participated in the October 28, 2006 Atlanta, Georgia meeting.
 - Seventy-three citizens completed the pre-survey, and 66 citizens completed the post-survey; 84 total citizens participated in the meeting.
3. Sixty-six citizens who were recruited for and participated in the November 4, 2006 Seattle, Washington meeting.
 - Sixty-two citizens completed the pre-survey, and 53 completed the post-survey; 66 citizens participated in the meeting.
4. Thirty-four citizens who were recruited for and participated in the November 18, 2006 Lincoln, Nebraska meeting.
 - Twenty-nine citizens completed the pre-survey, and 23 citizens completed the post-survey; 34 citizens participated in the meeting.
5. Seventy-five citizens who were recruited for and participated in the November 18, 2006 Syracuse, New York meeting.
 - Sixty-nine citizens completed the pre-survey and 59 citizens completed the post-survey; 75 citizens participated in the meeting.

For each of the five meetings, respondents were asked to complete an informed consent form and voluntarily complete the surveys. Demographic information about respondents is discussed in the Results section below.

Surveys. The pre-survey consisted of two sections: eight multiple-choice questions assessing knowledge about pandemic influenza and a section with four items asking opinions about values, community control measures, and who should make decisions about community control measures. 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 five-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 in Appendix 1.

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 two groups of people for individual interviews:

1. Stakeholders who participated in the two-day Washington, D.C. meeting
2. Citizens who participated in the Atlanta, Seattle, Lincoln, and Syracuse meetings

Citizens were asked to provide contact information on the informed consent forms if they were interested in participating in the interviews. The evaluators randomly selected a number of participants from each of the four citizen groups who provided their contact information and attempted to contact them by telephone and email. Those people who could be reached were selected to participate. For the stakeholders, nine were selected from the contact list and interviewed; seven of these respondents were stakeholders who had not participated in any of the citizen meetings and two respondents were citizens who had attended one of the state citizen meetings as well as the stakeholder meeting. Interviews with 11 Atlanta citizens, nine Seattle citizens, 11 Lincoln citizens, and 10 Syracuse citizens were used in the analysis.

Interview Questions. The interview questions for stakeholders and citizens asked how they perceived the information about pandemic influenza; the quality of the participation; 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 citizen deliberations 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 meeting were, how they found out about the meeting, and why they participated.

Procedures. Each randomly selected respondent was contacted to schedule an interview with the evaluators. Evaluation staff following an interview protocol conducted the interviews, which were recorded and transcribed.

Focus Groups

Respondents. At each of the four citizen meetings, participants were asked to volunteer to stay after the meeting and participate in a focus group. Respondents self-selected to join each focus group. Although exact numbers were not kept, each focus group included between eight and 14 participants.

Procedures. The same questions used in the interviews were used for the focus groups. The discussions were recorded and transcribed. Survey and focus group input was entered into a software program called *Atlas.ti*. Multiple raters identified themes in the answers from respondents.

Document Review

A document review was conducted to assess as a method to determine how the process was considered by policy makers. We reviewed the report produced as part of the public engagement process and the interim government report providing guidance regarding community control measures. The next phase of the evaluation will include individual interviews with policy makers to determine how the output from the public engagement process was considered and used in the formation of public policy.

Chapter 3: Evaluation Results - Participation and Recruitment

Reasons for Participation

The goal of the public engagement process was to recruit a sufficiently large number of citizens to participate in each meeting to have a diversity of perspectives and to allow breakout sessions of smaller groups. A “rule of thumb” goal for the citizen deliberations was to attract 100 participants at each of the four state sites; organizers believed that having large numbers of citizen participants would lend more credibility to the results. Preliminary observations and findings from the citizen interviews indicate the process was successful at recruiting and attracting citizens to participate in the deliberative process. Although no site reached the goal of 100 participants, each citizen meeting included enough citizens to have multiple small group discussions. Two hundred fifty nine citizens participated at the four sites: 84 in Atlanta, Georgia; 66 in Seattle, Washington; 34 in Lincoln, Nebraska; and 75 in Syracuse, New York.

Participants in the four local sites generally attended the public engagement sessions out of personal interest and/or for work related reasons. Some participants had extensive knowledge and a long-standing interest in the development of pandemic preparedness while others came to the meeting with virtually no previous exposure to the issue. The participants in all the cities who attended the session because of work reasons were more likely to have previous knowledge of pandemic issues than those who attended out of personal interest. Several of the participants interviewed in Atlanta had participated in a previous pandemic influenza public engagement process related to vaccination prioritization. The Atlanta participants were all more likely to have read material related to pandemics before attending this meeting than participants at other sites.

Email was the most common way that participants at local sites reported finding out about the meetings. Some received the email directly, while others had it forwarded to them by friends, colleagues, or supervisors. Those who did not receive notice by email could often point to a friend receiving an email, who passed it on to others. Many of those interviewed talked about receiving notice through networks to which they belonged to (e.g., volunteer or professional groups, civic groups, news groups).

Almost all local participants indicated that some of their motivation to attend a full weekend day of facilitated group process on pandemic influenza was related to a sense of personal responsibility, curiosity, or a desire to contribute to the dialogue. *“I believe strongly that our government is of the people, for the people, and by the people, so I really believe that the opportunity for the people to speak should be given a good deal of weight to governmental deliberations. This is one of the chances where we as a people, as a representative of the people, really get a chance to talk back to the government.”*

Some participants worked in settings that were planning for disasters, and others had very personal connections to high risk groups (e.g., chronically ill family member, world traveler). At least two people interviewed indicated that they had contracted the Hong Kong flu in 1968 and one had a grandfather who lived through the 1918 influenza pandemic. These personal experiences increased motivation to participate in a process that was perceived as both informational and a mechanism for influencing public policy.

“This was an opportunity to influence public policy and to make sure the priorities of me and the people I know are taken into account when making policy.”

“I believe it is our civic responsibility when asked by governmental agencies for feedback to provide as much opinion as possible. I saw it as an opportunity to influence public policy and to make sure the priorities of me and the people that we know are taken into account when public policy is being set.”

Diversity of Participants

A goal of the project was to attract a diversity of participants, both in terms of demographical characteristics and perspectives. It was not necessarily the goal to have the participants match the exact demographics of the United States or of the communities in which the meetings were held, but rather to have enough diversity to hear multiple perspectives from different sectors of the population. In this sense, it appears the process was successful. Participants represented 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, education, and income, although participants were not exactly representative of the general population in the four communities. Figure 1 shows age percentages for all four citizen deliberation sites. Participants represented a cross-section of ages, although the majority of citizens at each meeting site were 45 – 64 years of age. Lincoln had the largest proportion of citizen participants 65 years of age or older.

Figure 1
Percentage of Respondents by Age for Citizen Sites

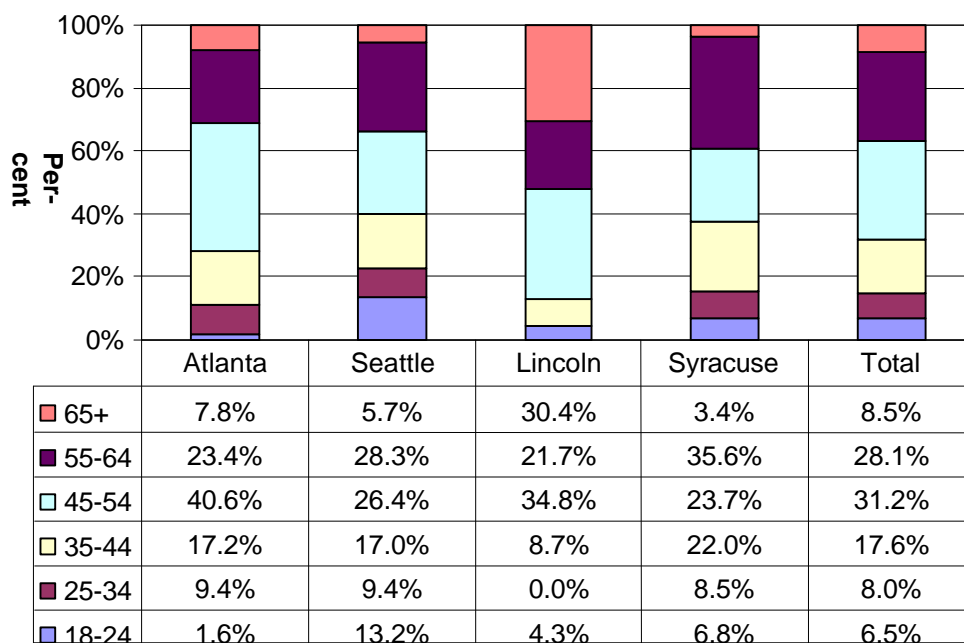


Figure 2 shows gender percentages for each of the four sites, indicating that participants in all four sites were predominately female. Syracuse had the highest proportion of females.

Figure 2
Percentage of Respondents by Gender for Citizen Sites

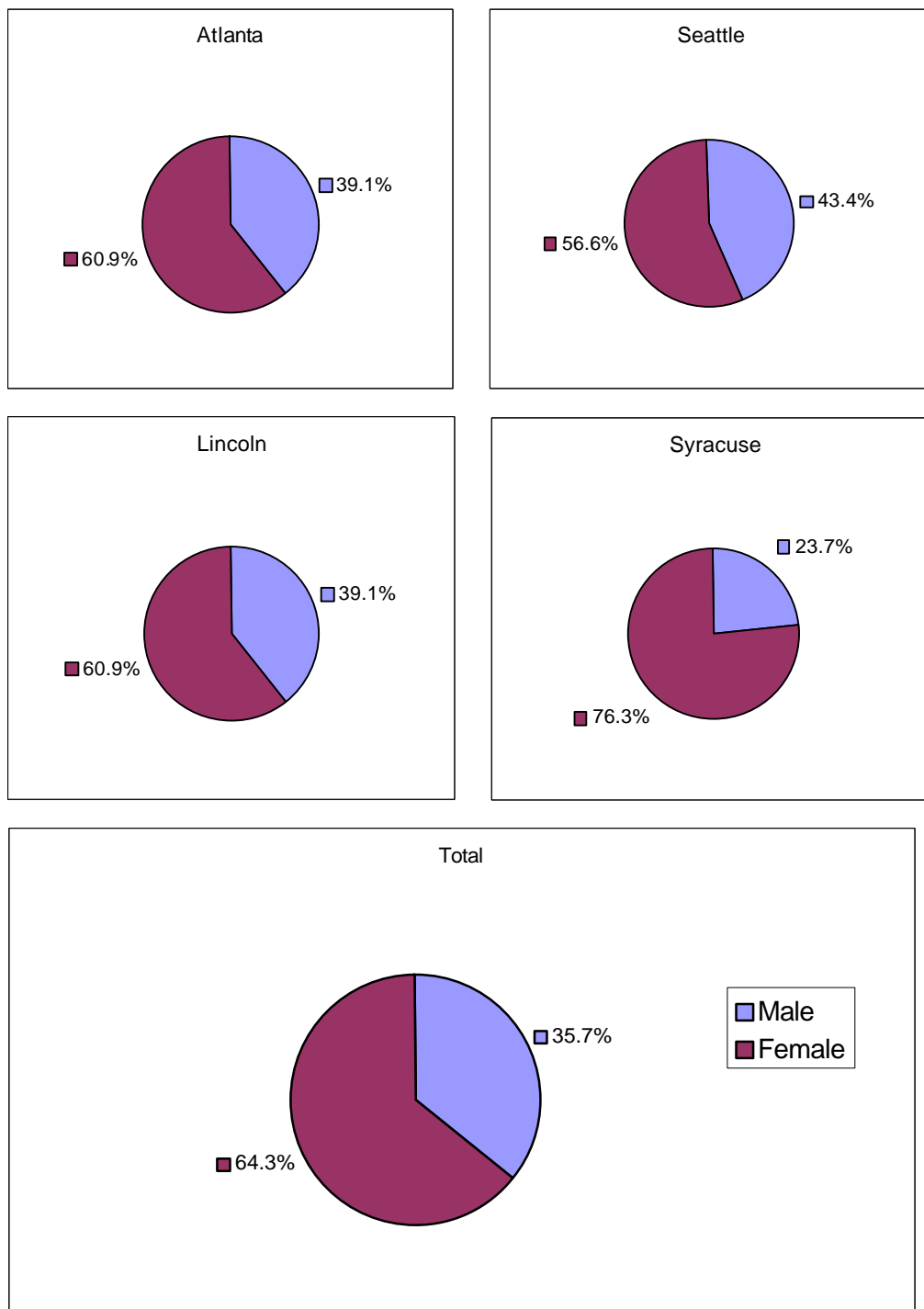


Table 1 shows race/ethnicity for each site and indicates there was a mix of racial/ethnic diversity across the four sites, although a large majority were Non-Hispanic White. One site included no Asian participants and another site included no Asian, Native American, or Black participants.

Table 1
Percentage of Respondents by Race/Ethnicity for Each Citizen Site

| Race/Ethnicity | Atlanta | Seattle | Lincoln | Syracuse | Total |
|-----------------|---------|---------|---------|----------|--------|
| Hispanic White | 4.0% | 1.6% | 3.8% | 13.0% | 4.0% |
| Hispanic Black | 0.5% | 1.6% | 0% | 0% | 0.5% |
| White | 60.2% | 68.3% | 79.2% | 78.3% | 74.7% |
| Black | 12.6% | 25.4% | 3.8% | 0% | 12.6% |
| Asian | 3.0% | 0% | 7.5% | 0% | 3.0% |
| Native American | 1.5% | 1.6% | 1.9% | 0% | 1.5% |
| Other | 3.5% | 1.6% | 3.8% | 8.7% | 3.5% |
| Total | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% |

Table 2 shows education levels across the four sites and indicates that education levels are higher than the general population. None of the sites had respondents with a level of education less than a high school degree. Over one-third of participating citizens had a graduate school degree.

Table 2
Percentage of Respondents by Education Level for Each Citizen Site

| Level of Education | Atlanta | Seattle | Lincoln | Syracuse | Total |
|--------------------------|---------|---------|---------|----------|-------|
| Less than high school | 0% | 0% | 0% | 0% | 0% |
| Some high school | 0.5% | 0% | 0% | 0% | 0.5% |
| High school graduate | 4.5% | 3.1% | 3.8% | 13.0% | 4.5% |
| Some college | 22.1% | 17.2% | 30.2% | 30.4% | 22.1% |
| College graduate | 29.1% | 26.6% | 34.0% | 26.1% | 29.1% |
| Some graduate school | 9.5% | 9.4% | 7.5% | 8.7% | 9.5% |
| Graduate school graduate | 34.2% | 43.8% | 24.5% | 21.7% | 34.2% |
| Total | 100% | 100% | 100% | 100% | 99.9% |

Figure 3 shows the percentages of respondents with children at home. Over 2/3 of respondents had no

children at home. Lincoln, which had the largest proportion of elderly participants, had the lowest proportion of participants with children.

Figure 3
Percentage of Respondents by Children Living at Home for Citizen Sites

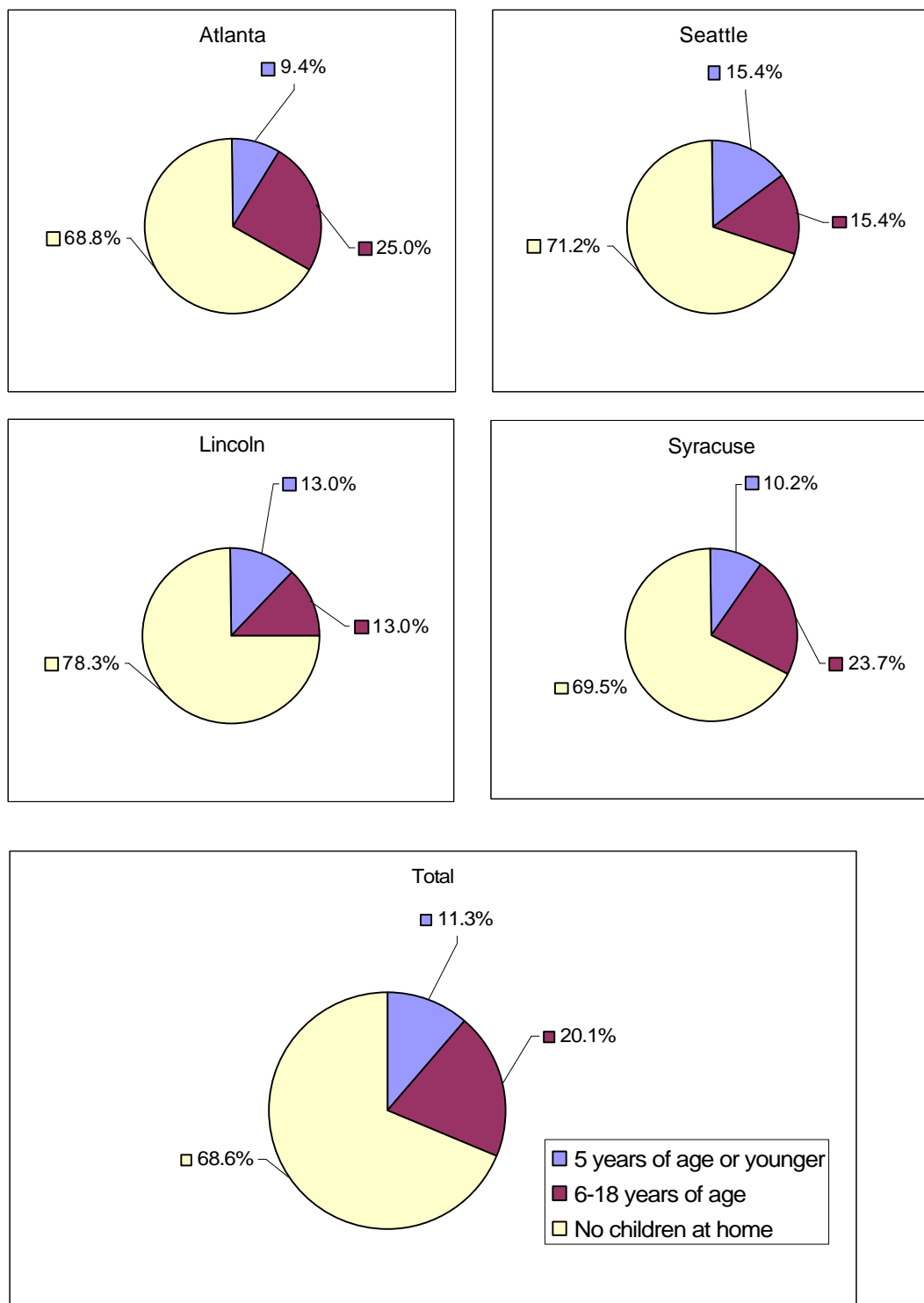


Table 3 shows income levels of participants. Participants in Atlanta had higher levels of income compared to other sites. Seattle included more low-income participants (\$15,000 or less) than other sites.

Table 3
Percentage of Respondents by Income Level for Each Citizen Site

| Annual Income | Atlanta | Seattle | Lincoln | Syracuse | Total |
|----------------------|---------|---------|---------|----------|-------|
| \$15,000 or less | 1.6% | 17.3% | 0% | 10.3% | 8.2% |
| \$15,001 - \$30,000 | 4.8% | 5.8% | 22.7% | 10.3% | 8.8% |
| \$30,001 - \$60,000 | 32.3% | 21.2% | 40.9% | 29.3% | 29.4% |
| \$60,001 - \$100,000 | 27.4% | 36.5% | 18.2% | 24.1% | 27.8% |
| \$100,001 or more | 33.9% | 19.2% | 18.2% | 25.9% | 25.8% |
| Total | 100% | 100% | 100% | 100% | 100% |

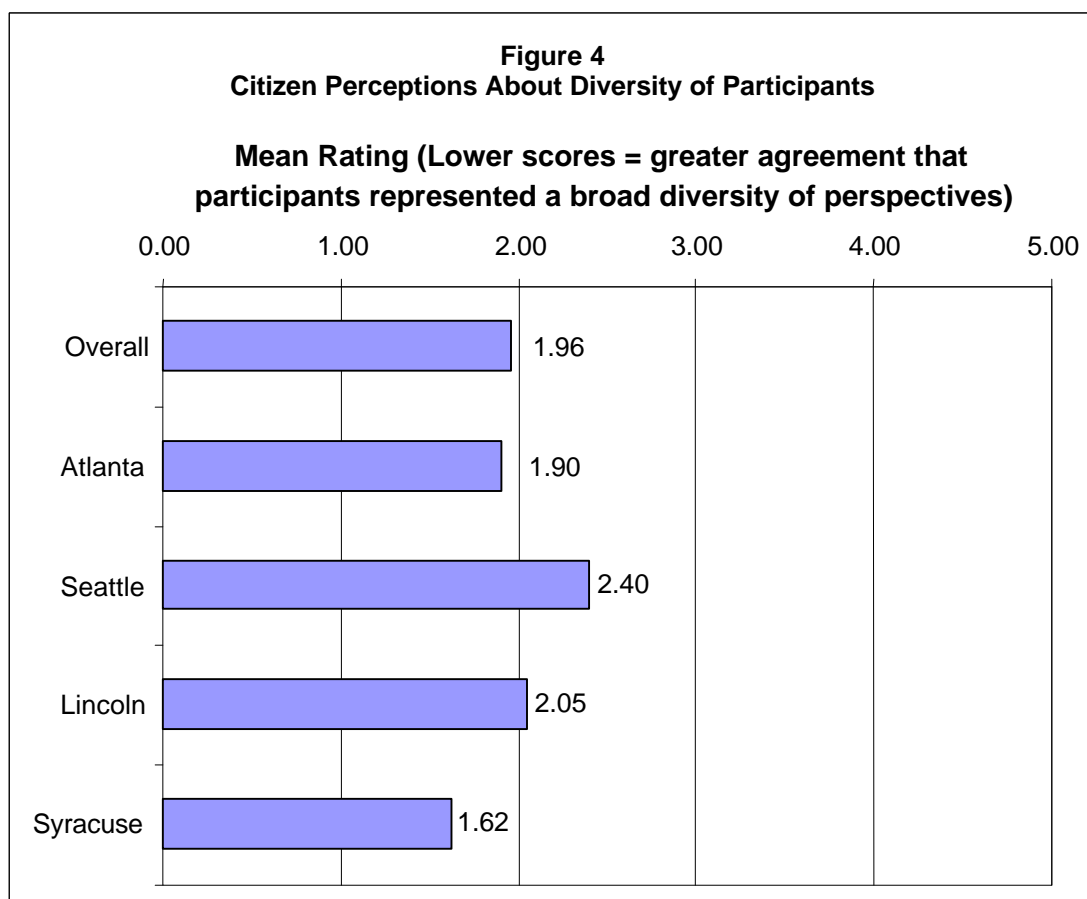


Table 4 compares the demographic characteristic from the four citizen meetings to the demographics of the broader population in the four communities. Participants in the four meetings were over-representative of the 45 – 65 age categories and under-representative of the younger age categories (18 – 34). Females were over-represented in comparison to community demographics. Whites and Native American participants were over-represented while Blacks, Asians, and Other Race/Ethnicity were under-represented. Hispanics participated in about the same proportion as the general population of the four communities. Participants in the four meetings had higher levels of education than the general populations of those communities. The percentage of participants with graduate degrees was over six times higher than the general population. Individuals with no college experience were substantially under-represented at the meetings. Individuals with higher incomes were over-represented at the meetings. The percentage of meeting participants with annual household incomes of \$100,000 or more was more than twice as high as the general population, and the percentage of participants with annual household incomes of \$30,000 or less was about half of the percentage of the population in the four communities.

Table 4
Comparison of Participant Demographics
to Community Demographics

| | Meeting Participants | Community Demographics | |
|-----------------|--------------------------|------------------------|-------|
| Age | 18-24 | 6.5% | 10.5% |
| | 25-34 | 8.0% | 18.0% |
| | 35-44 | 17.6% | 15.2% |
| | 45-54 | 31.2% | 12.5% |
| | 55-64 | 28.1% | 7.0% |
| | 65+ | 8.5% | 11.3% |
| Gender | Male | 35.7% | 49.1% |
| | Female | 64.3% | 50.9% |
| Race/ Ethnicity | Hispanic White | 4.0% | 4.7% |
| | Hispanic Black | 0.5% | |
| | White | 74.7% | 62.4% |
| | Black | 12.6% | 25.4% |
| | Asian | 3.0% | 5.4% |
| | Native American | 1.5% | 0.8% |
| | Other | 3.5% | 5.1% |
| Education | Less than high school | 0% | 5.4% |
| | Some high school | 0.5% | 11.4% |
| | High school graduate | 4.5% | 22.8% |
| | Some college | 22.1% | 19.4% |
| | College graduate | 29.1% | 27.8% |
| | Some graduate school | 9.5% | 13.3% |
| | Graduate school graduate | 34.2% | 5.4% |
| Income | \$15,000 or less | 8.2% | 21.2% |
| | \$15,001 - \$30,000 | 8.8% | 14.4% |
| | \$30,001 - \$60,000 | 29.4% | 28.3% |
| | \$60,001 - \$100,000 | 27.8% | 25.0% |
| | \$100,001 or more | 25.8% | 11.2% |

Figure 4 indicates participants in the four citizen meetings thought there was a broad diversity of perspectives by citizens at the meetings, although participants in Seattle were less likely to agree with this statement. Participants were asked to rate this item from one to five with one indicating strongly agree and five indicating strongly disagree.



Results from focus groups and interviews indicated that participants in local sites were pleased with the diversity of opinions expressed at the meetings. They thought participants reflected a “mosaic” of their communities, but did not represent all sectors well. Participants noted that there was some racial/ethnic and age diversity in all sites and cited concerns about the lack of “*disadvantaged people*” or those who “*worked to survive*” on low wages. They were also generally disappointed about the lack of young people and non-English speakers in the sessions. As one citizen stated, “*It was a very high concentration of older people*” The political orientation of participants was not assessed through the survey, but in a focus group a person who identified herself as a conservative, expressed her perception that there were not many other participants who shared her political orientation.

Suggestions for Improved Recruitment

Citizens gave suggestions for increasing diversity at future public engagement events. The majority of people interviewed indicated that they attended because they felt personally invited to attend via an email or personal contact. Few attended only because they saw an announcement in a newspaper. Even those who received notice through a listserv felt they were personally connected via their association with the trusted organization that sent them the notice. This approach led many who were interviewed to suggest that any outreach efforts to minority, marginalized or underrepresented groups be made through trusted sources. As one citizen indicated, “*Maybe more would have been there if someone had tapped them on the shoulder.*”

A common theme among the suggestions was that recruitment of these group members may be more effective if it is made more personally relevant to them: for example, enlist informal leaders within the groups or advertise through service providers, specialty newspapers or radio stations. Making the events convenient to attend was also frequently cited, primarily by altering the timing or location of the event. Nobody suggested stipends or monetary incentives for attendance, but it was suggested that on-site child care and provision of transportation could potentially increase attendance. Below is a list of the suggestions made by citizens to increase diverse representation at public engagement events.

Timing

- Hold the event on a different day of the week (other than Saturday)
- Attract shift workers by holding evening or night events or matching typical shift hours
- More advance notice of the event so people can make time to attend (more than a week)

Location

- Hold the event outside of urban areas to make it easier for rural voices to be heard
- Use video conferencing with on-site facilitation to increase number of simultaneous locations included in the event
- Hold the event within ethnic neighborhoods at places that are familiar and trusted – churches, community centers, gathering places, senior centers, youth centers
- Hold at a site that can safely provide on-site child care

Outreach

- Post event invitation in ethnic grocery stores and on neighborhood community boards
- Contact manufacturing companies and ask for posting on employee bulletin boards
- Distribute event invitations in different languages
- Ask inner city and ethnic churches to announce event from the pulpit and include information in church bulletins
- Enlist social service groups to distribute event information to their constituents
- Ask high school and college groups to distribute event information
- Sponsor internet links on school internet sites
- Advertise on relevant radio and television stations (e.g., Spanish channels; alternative radio stations; minority or college newspapers)
- Bring informal leaders of minority and marginalized communities to the table to endorse participation in the events or to extend personal invitations to members of their communities
- Overtly state that the event is ‘safe’ for immigrant community members to attend
- Provide transportation or make reimbursement for travel available on-site at end of event
- Give more information in advance about the process in terms people can understand

Stakeholder Diversity

Although the evaluation was not designed to assess the diversity of the stakeholder meeting, the desire to have included greater numbers of minorities and other disenfranchised populations was a theme that arose through the interviews. A citizen participant from the stakeholder meeting pointed out the lack of stakeholders from “*minority institutions or organizations for people of color.*” The lack of those present who represented marginalized people or organizations that served them was noted. One citizen described the stakeholder group as “*a lot of people pointed in the right direction, but because most people there have advanced degrees and they are fairly affluent, they don’t necessarily look through the lens of people who may not have those attributes. People can only view things from where they are perched.*”

The need for greater representation of minorities and marginalized populations at the stakeholder level in addition to the citizen forums was emphasized. “*We need to be a part of that discussion to raise concerns relative to our community. If it was a group of us, we may not be able to plan well for those who are affluent because we wouldn’t understand their needs.*”

Suggestions for enhancing participation of minorities and marginalized populations in the stakeholder group included the following:

- Recruit and invite scientists and professionals of color from minority medical institutions (e.g., historically black colleges; tribes)
- Increase representation from organizations representing the interests of minorities and marginalized people (e.g., social service sector; NAACP)
- Purposefully invite minority leaders who are not just from the faith community
- Continue to include citizen representatives in the stakeholder meetings
- Consider televising citizen forums; holding some in other languages

Chapter 4: Evaluation Results - Citizen and Stakeholder Knowledge

Citizen Knowledge

Citizens and stakeholders were given an eight-item knowledge test at the beginning of each session and again at the end. As indicated in Table 5, average scores for citizens increased significantly from the pre-test to the post-test ($F(1,184) = 162.265, p < .001$). The level of knowledge on all items, but one, increased significantly from the pre-test to the post-test indicating that the presentation of information and the discussions improved citizen understanding of pandemic influenza. The only question that did not increase significantly (Who is at risk when a new influenza virus appears that has never been seen before?), was answered correctly by a large majority of citizens on the pre-test.



Table 5
Change in Citizen Knowledge

| Question | % of people who answered correctly | |
|--|------------------------------------|-----------|
| | Pre-test | Post-test |
| Q1: How soon after someone is infected with an influenza virus will they get sick? | 54.3% | 80.9% * |
| Q2: When will the next pandemic occur? | 65.4% | 83.0% * |
| Q3: About how many people do you think die in a typical year from flu in the United States? | 42.6% | 83.5% * |
| Q4: Who is at risk when a new influenza virus appears that has never been seen before? | 93.6% | 97.3% |
| Q5: How many pandemics have occurred over the last 100 years? | 64.7% | 97.3% * |
| Q6: What causes a flu pandemic? | 68.1% | 81.9% * |
| Q7: About how many people could become ill in the United States during a severe pandemic? | 21.8% | 34.0% * |
| Q8: Which of the following is not considered a viable option to control the spread of flu during a pandemic? | 37.8% | 63.8% * |
| * indicates a significant increase in knowledge at $p < .05$ | | |

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

| | |
|-------------------------|------|
| Atlanta | 1.74 |
| Seattle | 1.98 |
| Lincoln | 1.77 |
| Syracuse | 1.71 |
| Citizen Meeting Average | 1.80 |
| Stakeholders | 1.82 |

Information obtained through citizen focus groups and interviews indicate the information presented at the meetings was universally appreciated by participants and seemed to strongly influence the outcomes generated at the meetings. *“There is a political nature to a lot of things, and so truthfulness is important. And I felt like the information I received was truthful.”*

Participants who had previous knowledge about pandemics reported obtaining it from newspaper and magazine articles, television news, the internet, and books. Several people reported reading the books written about the 1918 influenza prior to coming to the meeting. *“I’ve done a ton of reading and talking and listening to people, and I wanted to see if what was said in that meeting matched up with what I had learned from a variety of sources, and it did.”*



Although much of the information presented at the local meetings was known, almost everyone reported hearing some new information in the presentations. *“I did not know the difference between an epidemic and a pandemic. I used that at work. I asked some of the nurses at work if they knew the differences between an epidemic and pandemic....I was surprised at how many didn’t know the difference between an epidemic and a pandemic.”* *“I learned more at this meeting than I had at a number of years at public health.”* For those who had no previous exposure to information about pandemic influenza, the information was stunning: *“Oh my God, people need to know this!”*

Participants thought the presentations were understandable and reported using it throughout the day in both small and large group discussions. Some people referenced concern about inconsistencies they detected in information presented via media versus the information presented at the meeting. Some speculated that the decisions reached at the meeting might have been different if the information

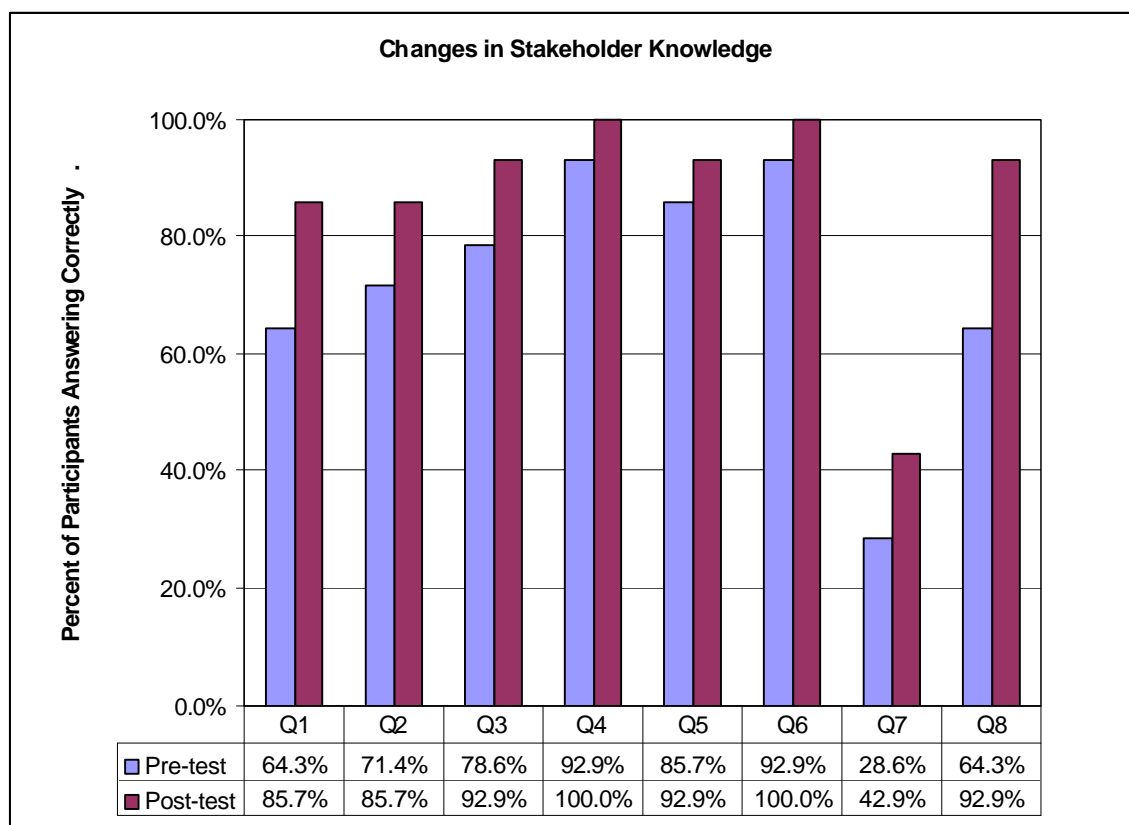
presented was different. *“We all felt we had enough information to make decisions; but when I heard a CDC person later on the radio who gave information about closing the schools as being ineffective, I thought well doggone it, we should have had that information at that daylong event – we may have made different decisions if we had that information.”*

Several participants recommended that future presenters at similar meetings consider using experiential means of communicating crucial information. One participant gave an example of a presenter coating their hand with glitter, shaking hands with people as they came into the meeting. When talking about transmissibility the presenter asks everyone to examine their hands for glitter – illustrating how easy it is for viruses to spread. Other examples included distribution of written, illustrated, or interactive briefing materials to participants prior to the meeting so the presentations could be shortened and more interactive when in person.

Stakeholder Knowledge

Stakeholders also gained knowledge during the process (see Figure 5). Overall, knowledge for stakeholders increased significantly from the pre-test to the post-test ($F(1,14) = 5.2, p < .04$), indicating the process was successful in increasing the knowledge of participants at the stakeholder meeting. Since many of the stakeholders were experts in the field of pandemic influenza, it is not surprising that average pre-test scores were higher for the stakeholders than for the citizens.

Figure 5



The general perception of those interviewed was that attendees at the stakeholder meeting came with a range of knowledge about influenza and pandemic issues, though each person interviewed believed that his or her personal knowledge level was high. Stakeholders appreciated the need for an opening presentation that focused on information related to influenza and pandemics, though most reported that they relied on their previous knowledge more heavily in the small group discussions. The value of the presentation for several of the stakeholders was that it used non-technical language from a lay perspective rather than from a stricter scientific or medical viewpoint. This *“set the tone for the rest of the meeting”* according to one of the stakeholders.

Citizen participants in the stakeholder meeting appreciated the presentation, though they also reported relying heavily on their previous knowledge for much of the discussion. Interestingly, the citizens felt well informed, yet at least one stakeholder was concerned about the citizen’s lack of understanding of pandemic influenza. Conversely, at least one of the citizens expressed concern about the lack of understanding by stakeholders of how citizens might be affected by their decisions. *“Some of the things I was saying, they were interested in it, not just because they should have an interest, it was almost like it was new information for them.”*

Chapter 5: Evaluation Results - Quality of Deliberations

Citizen Results

The post-surveys indicate citizens generally believed the process was of high quality. Table 6 shows average scores for ratings of the process on a scale one to five, with one representing strongly agree and five representing strongly disagree. For the first six items, a higher quality process is associated with a lower numerical score. For the last two items, a higher quality process is associated with a higher numerical score. In all four cities, citizens rated the process high on all dimensions. The highest rated dimensions were citizens felt comfortable talking and thought other felt comfortable talking; the lowest rated dimension (although still receiving an overall high rating), was that important points were left out of the discussion.

Although there were not significant differences across the four sites, there were some significant differences for individual cities:

- Citizens in Seattle reported feeling less comfortable talking than did people in the other cities
- Citizens in Seattle were less likely to believe the process produced credible, relevant, and independent information than people in the other cities.
- Citizens in Seattle were less likely to believe the process produced a credible outcome compared to people in the other cities.
- Citizens in Atlanta and Seattle were more likely to indicate that the conversation was dominated by one person or a small group of people.

| Table 6 Average Citizen Ratings of Process by Site | | | | | |
|--|---------|---------|---------|---------|----------|
| | Mean | | | | |
| Statement | Overall | Atlanta | Seattle | Lincoln | Syracuse |
| I think other people in this discussion felt comfortable talking. | 1.28 | 1.29 | 1.36 | 1.23 | 1.24 |
| I felt comfortable talking in this discussion. | 1.29 | 1.16 | 1.64 | 1.18 | 1.18 |
| This discussion was fair to all participants. | 1.33 | 1.34 | 1.53 | 1.27 | 1.16 |
| I think this process helped me better understand the types of trade-offs involve. | 1.35 | 1.21 | 1.49 | 1.27 | 1.44 |
| I think this process has produced credible, relevant, and independent information. | 1.41 | 1.26 | 1.68 | 1.32 | 1.38 |
| I think this process produced a valuable outcome. | 1.54 | 1.42 | 1.85 | 1.41 | 1.47 |
| Important points or perspectives were left out of the day's discussion. | 3.40 | 3.34 | 3.32 | 3.23 | 3.62 |
| One person or a small group of people dominated the discussion. | 4.06 | 3.97 | 3.64 | 4.36 | 4.40 |

Information from citizen focus groups and interviews indicated most participants appreciated and applauded the structure of the meetings at the local public engagement sites. *“I thought it was well presented. I thought it was well moderated. I didn’t think [they] were trying to drive the solution towards a predefined answer.”*

There was a noticeable difference in style among facilitators at single sites, though this was only noticeable to observers, organizers, and experts who moved among tables. Participants generally appreciated the skill level of their facilitator and indicated that organized facilitation helped focus their discussion and ensure that all participants had the opportunity to speak. *“I walked away from this one thinking it was extremely well organized, it was well planned. The people that facilitated, facilitated very well.”*

“I really felt like the process was one of the best facilitated processes that I have participated in in a very long time.”

The expectation that everyone’s opinion was important was set by other participants as well. One participant reported being hesitant to speak until feeling safe with her small group. *“I was encouraged by other members of the group to enter the conversation.”* Many of the participants thought there should be more time allotted for small group discussions. They found value in getting to know others in their group and grew more comfortable sharing true opinions with them as the day progressed. They also reported “enjoying” the interactions with others in both small and large group forums. *“Anybody who wanted to say something was able to do that. It was respectful, it was controlled, but it wasn’t controlled to the extent that people couldn’t say what they wanted to.”*

There were mixed reviews about the inclusion of electronic polling as part of the process. Some found it valuable, while others thought it detracted from the process, taking time away from deliberation and discussion. Overall most participants indicated that the experience of participating in the daylong event was one they would repeat and recommend to friends. Most will be watching media outlets for evidence that their information was used by policy makers. Comments about the event were generally positive and reflected both an interest in the process and an appreciation for the way their input was sought. *“This was a great opportunity to make use of concerned citizens in a meaningful and structured way.”*
“I was delighted to be a part of it and it is something that I hold dear.”

Stakeholder Results

Table 7 shows the process rankings by stakeholders. Overall, stakeholders thought the process was of high quality, although slightly less so than citizens. The highest rated items were that stakeholders felt comfortable talking in the discussion and that the discussion was fair to all participants. The lowest rated items were that important ideas were left out of the discussion and one person or group dominated the discussion.

| Table 7 Average Stakeholder Ratings of Process | | |
|--|-------------|----------------|
| Statement | Mean | Std Dev |
| I felt comfortable talking in this discussion. | 1.41 | 0.87 |
| This discussion was fair to all participants. | 1.47 | 0.80 |
| I think this process helped me better understand the types of trade-offs involved in using community control measures. | 1.59 | 0.87 |
| I think other people in this discussion felt comfortable talking. | 1.59 | 1.06 |
| I think this process produced a valuable outcome regarding community control measures. | 1.65 | 0.86 |
| I think this process has produced credible, relevant, and independent information. | 1.65 | 0.93 |
| Important points or perspectives were left out of the day's discussion. | 3.59 | 1.28 |
| One person or a small group of people dominated the discussion. | 3.94 | 1.30 |

All of those interviewed from the stakeholder meeting expressed general satisfaction with the meeting process. All thought that adequate time had been dedicated to presentation of basic information, with citizen participants expressing the most appreciation for the presentation. *"I was really impressed with the overall structure and the handling with how information was shared."*



Several of the stakeholders indicated that the time allotted for sharing basic information could have been shortened. One person suggested that stakeholders be invited to skip the presentation because of the advanced knowledge most had about influenza. Sitting through the presentation for half of a day led at least one stakeholder to conclude that their time was not valued and that they were not contributing as fully as they would like. *"With my schedule I'm not sure I had to be there for that part of it. I think for most people though, it was good information. I'm not as confident that my input was as useful until the small group breakout."*

One stakeholder said that they would have liked more time to ask questions of the government representatives at the meeting but *“didn’t feel this was the forum for it.”* The small group discussion and open forum were highlights and deemed the most valuable part of the process by those interviewed. An unintended positive consequence of the small discussions was the informal networking that was done by stakeholders. One person summed up the benefit of side discussions by saying that it enabled her to *“talk with people that I don’t have day to day contact with”* from industry and government.

Although additional time for discussion would have been welcomed, all interviewed understood that the topics were too broad for an exhaustive discussion and appreciated the timeframes allotted. Limited time forced participants to narrow their discussion. Facilitation at the stakeholder meeting was viewed by all those interviewed as exceptional. They appreciated the advance planning and skill of their small group facilitators.

The primary complaint regarding the stakeholder meeting centered on a perceived disconnect between the discussion group challenge heard by meeting participants and the one that seemed to be intended by a major meeting organizer. Meeting participants reported that they felt *“disheartened,” “disappointment,”* and *“a sense of failure”* after comments were made by a meeting organizer about the content of their work. This did not diminish the view of stakeholders that the quality of discussion in the small groups was worthwhile and valuable. *“When you get that many smart people in the room and you get those ideas floating around, you get some really great insights. People were really great about thinking outside the box.”* Another stakeholder said *“I think the groups did a better job than they were given credit for.”* A recommendation that surfaced as a result of this problem was that meeting organizers have agreed upon process and product goals that are shared in writing with participants for all meeting activities.

Chapter 6: Evaluation Results - Impact of Deliberations on Beliefs

Social Values

Survey results indicate some opinions regarding social values, goals, and priority groups changed for stakeholders and citizens after they received information and deliberated about community control measures. This change is significant in that it indicates the deliberative process actually influences participants thinking. Table 8 indicates that social order, responsibility, utilitarianism, and equality increased in importance following the deliberation. It is possible that after the knowledge presentation, the discussion of ethics and deliberating with fellow citizens, participants became more aware of how social values related to the implementation of community control measures, which changed their ratings.

High importance was generally placed on safety and security, social order, responsibility, utilitarianism, respect for life, and equality. As indicated by the standard deviations for these higher rated values, citizen ratings tended to converge more after the process (i.e., there was greater agreement at the end of the process about the higher rated values). Lower importance was placed on the values of personal growth, prosperity, independence, and freedom. For these lower rated values, there were not major changes from pre to post test.

Table 8
Changes in Social Value Ratings by Citizens

| Social Value | Pre-test Mean (Std Dev) | Post-test Mean (Std Dev) | ANOVA F-value | ANOVA p-value |
|---------------------|------------------------------------|-------------------------------------|--------------------------|--------------------------|
| Safety & Security | 1.32 (0.78) | 1.24 (0.60) | 1.723 | .191 |
| Social Order | 1.59 (0.91) | 1.44 (0.73) | 4.974 | .027* |
| Responsibility | 1.64 (0.91) | 1.44 (0.68) | 8.063 | .005* |
| Utilitarian | 1.80 (1.06) | 1.52 (0.89) | 14.329 | <.001* |
| Respect for Life | 1.61 (0.91) | 1.58 (0.87) | 0.204 | .652 |
| Equality | 2.12 (1.22) | 1.88 (1.07) | 6.523 | .012* |
| Personal Growth | 3.10 (1.35) | 3.06 (1.44) | 0.177 | .674 |
| Prosperity | 3.58 (1.19) | 3.48 (1.24) | 1.205 | .274 |
| Independence | 3.44 (1.29) | 3.49 (1.27) | 0.240 | .625 |
| Freedom | 3.51 (1.18) | 3.57 (1.27) | 0.309 | .579 |

* indicates a significant change at $p < .05$



Table 9 shows the changes in social value ratings by stakeholders. One value (responsibility) increased significantly from the pre-test to the post-test. Other social values such as social order, prosperity, and independence increased in importance from pre-test to post-test, but were not statistically significant, likely due to small sample size. The stakeholder ratings on the post-test survey were similar to the ratings of citizens; the top six rated values were the same for stakeholders and citizens. As with citizen ratings, stakeholders were more closely in agreement about the top rated values after the process than before.

Table 9
Changes in Social Value Ratings by Stakeholders

| Social Value | Pre-test Mean (Std Dev) | Post-test Mean (Std Dev) | ANOVA F-value | ANOVA p-value |
|-------------------|----------------------------|-----------------------------|------------------|------------------|
| Safety & Security | 1.31 (0.63) | 1.15 (0.38) | 1.000 | .337 |
| Social Order | 1.54 (0.66) | 1.23 (0.44) | 2.182 | .165 |
| Responsibility | 2.08 (1.04) | 1.23 (0.44) | 9.553 | .009* |
| Utilitarian | 1.46 (0.78) | 1.38 (0.51) | 0.133 | .721 |
| Respect for Life | 1.85 (0.80) | 1.77 (0.73) | 0.188 | .673 |
| Equality | 2.92 (1.55) | 2.77 (1.59) | 0.170 | .687 |
| Prosperity | 4.00 (1.00) | 3.46 (1.20) | 2.625 | .131 |
| Independence | 4.00 (0.58) | 3.54 (1.33) | 1.728 | .213 |
| Freedom | 3.92 (1.04) | 3.69 (0.95) | 0.346 | .461 |
| Personal Growth | 4.00 (1.47) | 4.00 (0.91) | 0.000 | 1.000 |

* indicates a significant change at $p < .05$

Acceptability of Control Measures

Table 10 shows citizen acceptability of community control measures. In general, citizens found the community controls acceptable for their community. The least acceptable community control measure after deliberations was quarantine at home if exposed to someone else who was ill. The process that citizens went through during the day appeared to influence their thinking about community control measures. Community controls that were significantly more acceptable after the deliberations were: isolation of ill persons at home, canceling events where large groups of people are expected to gather, not allowing kids to congregate outside of schools and day care centers, and encouraging businesses to use alternative work locations. As indicated by the lower standard deviations, for those community control measures significantly more acceptable on the post-test, there was more agreement by citizens.

Table 10
Citizen Acceptability of Community Controls

| Community Control | Pre-test Mean (Std Dev) | Post-test Mean (Std Dev) | ANOVA F-value | ANOVA p-value |
|-------------------------------------|----------------------------|-----------------------------|------------------|------------------|
| Self-quarantine | 1.87 (1.10) | 1.74 (1.07) | 2.279 | .133 |
| Isolation if ill | 1.56 (1.02) | 1.32 (0.88) | 7.492 | .007* |
| Cancel events with large gatherings | 1.53 (0.90) | 1.25 (0.70) | 20.384 | <.001* |
| Close K-12 schools | 1.68 (0.90) | 1.61 (0.97) | 0.715 | .399 |
| Close day care centers | 1.76 (0.94) | 1.64 (0.98) | 2.053 | .154 |
| Not allow kids to congregate | 1.98 (1.17) | 1.65 (1.04) | 18.484 | <.001* |
| Encourage telecommuting | 1.22 (0.56) | 1.14 (0.51) | 3.554 | .061 |
| Encourage flexible work schedules | 1.34 (0.71) | 1.27 (0.68) | 1.498 | .223 |
| Encourage alternate work locations | 1.61 (0.91) | 1.38 (0.73) | 9.810 | .002* |

* indicates a significant change at $p < .05$

Compliance

Table 11 shows the change in compliance with community control measures from the pre-test to post-test. Citizens indicated they would be likely to comply with community control measures, both before and after the deliberations. As with the acceptability of community control measures, the process seemed to influence thinking about compliance. After the deliberation, people were significantly more likely to indicate that they would not attend large gatherings. For work related items, although no single item was statistically significant, there was a trend that citizens were more likely take greater advantage of flexible work schedules and alternate work locations after deliberation.

In general, people indicated they were likely to take advantage of all of these options if presented by their workplace. With regard to the child related items, citizens indicated a greater likelihood to keep their children home from school and daycare after the deliberation. Citizens were more in agreement after participating in the public engagement process about the community control measures that increased significantly in acceptability. Hence, not only did participants change their opinions about community control measures, they tended to agree more about certain items as a result of their participation.

Table 11
Citizen Compliance with Community Controls Pre and Post test

| Community Control | Pre-test Mean (Std Dev) | Post-test Mean (Std Dev) | ANOVA F-value | ANOVA p-value |
|--|-------------------------|--------------------------|---------------|---------------|
| Stay home if contact with ill person | 1.63 (1.02) | 1.60 (1.02) | 0.137 | .711 |
| Stay home if ill | 1.22 (0.61) | 1.16 (0.55) | 1.762 | .186 |
| Not attend events where large groups are expected to gather | 1.28 (0.63) | 1.15 (0.50) | 9.060 | .003* |
| Take advantage of flexible work schedules | 1.36 (0.85) | 1.27 (0.77) | 1.607 | .207 |
| Take advantage of telecommuting | 1.43 (1.00) | 1.55 (1.11) | 1.867 | .174 |
| Take advantage of alternate work locations | 1.65 (1.23) | 1.55 (1.13) | 1.346 | .248 |
| Keep your child home from school | 1.34 (0.72) | 1.13 (0.56) | 14.012 | <.001* |
| Keep your child home from daycare | 1.34 (0.72) | 1.17 (0.63) | 5.466 | .022* |
| Keep your child from other children outside of school or daycare | 1.45 (0.89) | 1.37 (0.80) | 1.392 | .242 |

* indicates a significant change at $p < .05$

Perceptions about Change in Beliefs

Results from the citizen focus groups and individual interviews indicated the process of deliberation and discussion in both small and large group settings, along with the information presented, influenced participant views about social control measures but did not necessarily change their opinions. However, the participants were either unaware their ideas changed or minimized the impact of the process.

Participants reported that the discussions helped them to be *“more open to considering other points of view,”* though their own point of view was still unchanged. *“I don’t have any children, so it caused me to think more about what the effect would be on other people and how that would eventually affect me.”* Those participants who reported enjoying diversity of opinions in their small groups were more likely to comment positively about the value of deliberation.

Participants in the stakeholder meeting had similar views. Although results from the surveys indicate that opinions about values, acceptability and compliance changed over the course of the meeting, none of those interviewed said that their beliefs or opinions changed as a result of the discussion or process. Most indicated that hearing other viewpoints in the small group discussion helped broaden or strengthen their views, but did not significantly change them. Several of those interviewed wondered if some stakeholders could fairly represent their personal beliefs in the discussion. *“The non-governmental workers shared true beliefs and opinions. Governmental workers clearly understand the pecking order. I think some of their basic, underlying beliefs may not be supported by the higher ups.”*

Chapter 7: Evaluation Results - Decision Authority

Perceptions about Who Should Make Decisions

Citizens and stakeholders were asked who or what entity should make decisions about community control measures. Although this issue was not explicitly addressed during the meetings, assessing citizen and stakeholder responses to these questions provide a sense of participant preferences for decision-making authority for community control measures. Overall, citizens and stakeholders preferred that 1) some government unit make the decisions rather than individuals themselves, 2) local or state units of government make decisions rather than federal government, and 3) health departments make the decisions rather than unspecified government entities.

Citizens were most likely to believe that local health departments should make decisions about community control measures (see Table 12). Citizens from the Atlanta meeting were more likely than citizens from other meetings to indicate the Federal Government should make these decisions; this higher ranking may be because the Centers for Disease Control and Prevention (CDC) is located in Atlanta. In the focus groups and interviews, Atlanta participants pointed out that the CDC was a government entity with special expertise in medical issues. They generally viewed the CDC as local though it was a federal agency. The CDC was not necessarily viewed as a government entity by participants at other sites. They viewed policy makers as legislators and government officials who would take into account information provided by medical experts like those in public health or at the CDC. Most viewed the CDC and public health officials as more trustworthy than elected officials when making decisions about community control measures. Some hoped that there would be consistency in decisions related to community control measures from state to state and country to country.

Table 12
Changes in Citizen Ratings Regarding who
Should Decide Community Control Measures

| | Pre-test % | Post-test % |
|---------------------------|-------------------|--------------------|
| Individuals themselves | 3.6% | 4.2% |
| Local health department | 30.7% | 36.1% * |
| City or county government | 13.3% | 12.7% |
| State Health Department | 27.7% | 22.9% * |
| State government | 9.0% | 4.8% * |
| Federal government | 15.7% | 19.3% * |

* indicates a significant change at $p < .05$

For stakeholders, the top two entities were local and state health departments (see Table 13). Rankings of the different entities changed after citizens and stakeholders went through the process. For citizens, the largest shifts in opinion

regarding who should determine what controls measures are adopted or implemented are away from the state level (state government and state health department) and toward local health departments and somewhat toward the federal government. For stakeholders, after the deliberation, people shifted toward preferring more local determination in the adoption of control measures.

Table 13
Changes in Stakeholder Ratings Regarding who
Should Decide Community Control Measures

| | Pre-test % | Post-test % |
|---------------------------|------------|-------------|
| Individuals themselves | 7.7% | 7.7% |
| Local health department | 30.8% | 30.8% |
| City or county government | 0% | 7.7% * |
| State Health Department | 30.8% | 30.8% |
| State government | 15.4% | 15.4% |
| Federal government | 15.4% | 7.7% * |

* indicates a significant change at $p < .05$

Perceptions about Voluntary/Involuntary Measures

Citizens and stakeholders were asked whether community control measures should be voluntary or mandatory. As shown in Table 14, although the majority of participants believe community control measures should be mandatory, there was a significant shift toward believing that control measures should be voluntary after the deliberations.

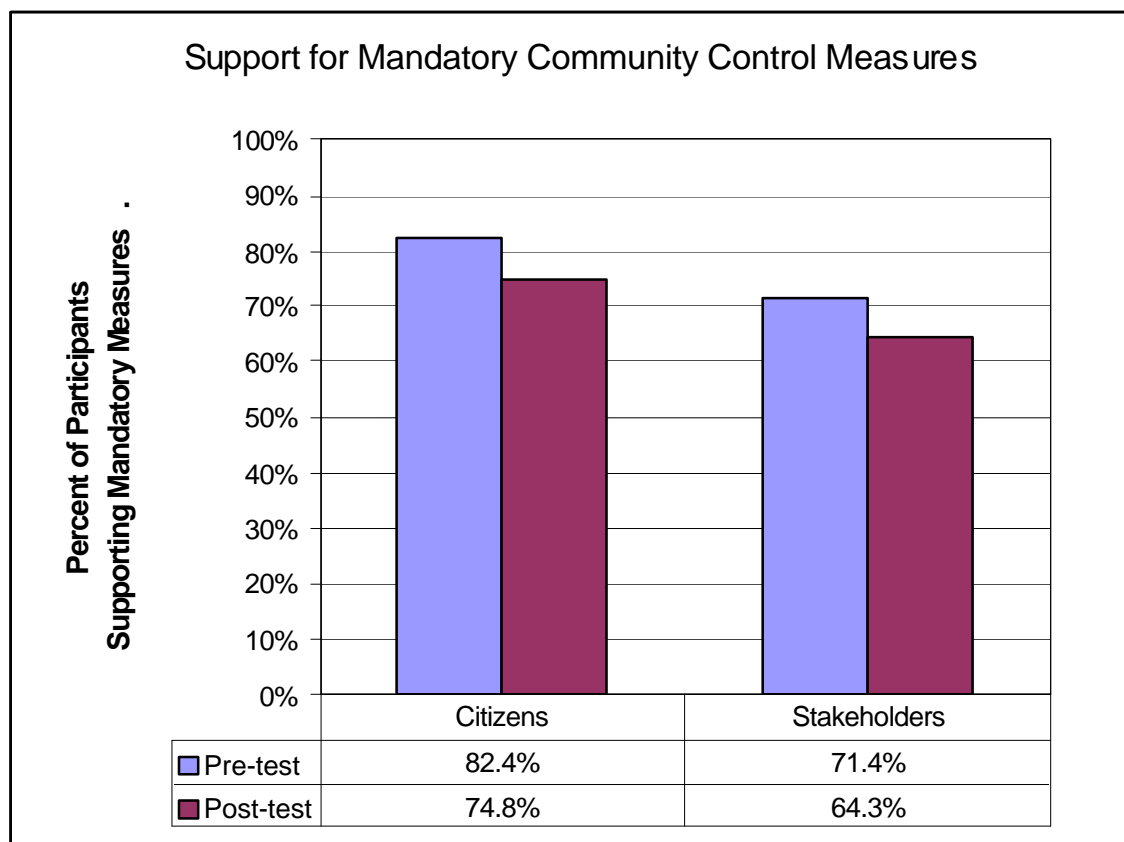
Table 14
Citizen Ratings of Whether Community Control Measures
Should be Voluntary or Mandatory

| | Pre-test % | Post-test % |
|-----------|------------|-------------|
| Voluntary | 17.6% | 25.2% * |
| Mandatory | 82.4% | 74.8% * |

* indicates a significant change at $p < .05$

Similar results were found for the stakeholders, although the pre- and post-survey differences were not significant (see Figure 6). Overall, stakeholders were more likely than citizens to believe that community control measures should be voluntary.

Figure 6



Chapter 8: Evaluation Results - Stakeholder Perception of Citizen Input and Anticipated Use by Policy Makers

Perceptions of Citizen Input

The value of citizen input for the stakeholders was great. As stated by one stakeholder: *“We have to trust the public, we have to trust the citizen group, that is why we are there...If we were to start the process just going on our own, we may have come up with other things.... But absolutely, we stayed right to it, we tried to address the most important citizen issue; that is what we focused on. I wish we had the opportunity to be more in depth with the citizen responses, I think we had to brush over it a little bit.”*

They reported receiving limited information in advance of the stakeholder meeting about the way the citizens voted regarding control measures. Some thought that more detailed information could have been shared about the four citizen groups in advance of the stakeholder meeting. One person suggested that additional time be set aside for stakeholders to review citizen forums in addition to or instead of presenting basic influenza information. The stakeholders interviewed said they were very impressed with the *“depth of thought”* that seemed to come out of the four citizen groups. One stakeholder compared citizen engagement in public health decisions to the work of a jury: *“It kind of reminded me of the jury system – that although you think sometimes that the public doesn’t get it, if you give them the right information they really do get it and make reasonable decisions based on the information given.”*

The citizen participants felt included and listened to by other stakeholders. The experience of engaging in discussion with stakeholders was taken seriously by both citizens interviewed. *“Just by having a seat at the table and having a voice, we felt very empowered – all of us. This is going to spur all of us to become much more active.”*

Anticipated 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 community controls. *“People will be more willing to comply [with social control measures] if they feel like they have been heard, and if they also feel that the people who make policies have an understanding of where the average citizen might be.”*

Table 15 shows citizen ratings for these two question (on a one to five scale with one being strongly agree and five being strongly disagree) across all sites. Citizens in Seattle were less likely to believe the



process would increase public support for community control measures and that officials would use their input than did people in the other cities (although the latter was not statistically significant).

Table 15
Citizen Perceptions about the Impact of the Input by Site

| | Mean | | | | |
|--|---------|---------|---------|---------|----------|
| Statement | Overall | Atlanta | Seattle | Lincoln | Syracuse |
| I think this process will increase the public's support of the decision ultimately made... | 1.89 | 1.77 | 2.26* | 1.73 | 1.76 |
| I think officials will use our input in their decisions... | 1.94 | 1.92 | 2.21 | 1.86 | 1.75 |

* indicates a significant difference at $p < .05$ from all other cities

Table 16 shows the stakeholder perceptions regarding impact. Generally, stakeholders thought the process would be used by policy makers and increase the public's support. The ratings by stakeholders were similar to those of the citizens.

Table 16
Stakeholder Perceptions about the Impact of the Input

| Statement | Mean | Std Dev |
|---|------|---------|
| I think this process will increase the public's support of the decision ultimately made on how to use community control measures. | 1.88 | 0.99 |
| I think officials will use our input in their decisions about how to use community control measures. | 2.00 | 1.00 |

The citizen focus groups and interviews indicate most people were generally satisfied with what they thought were the outcomes of the meeting. *"The powers that be want to know what the average citizen thinks and also where their head is, and what they think is important, and I think it was really an important opportunity to do that."*

Several people, however, were unclear about what the actual outcomes were. They understood that a summary of their opinions were going to be forwarded to policy makers, but were unsure that any other concrete outcomes were achieved at the meeting. Asking about the outcomes of the meeting prompted several participants to talk about their opinions regarding community control measures. They expressed

concern about logistics related to implementation of the proposed measures, offered suggestions about alternate measures, and discussed their perceptions of what the likely outcomes might be when policy makers had to make decisions about the measures. *“I walked away with a lot to think about it. I also walked away with some feelings that perhaps even though some of the measures might be really uncomfortable or difficult, some of them might really help.”*

An unintended consequence of the public engagement process may be that the information gained through the citizen meetings is communicated beyond the people who attended the meetings. As expressed by one citizen: *“The situations and the solutions don’t become quite so black and white. I think it got a lot of people thinking. And probably when they left – for at least another couple of weeks – it was something they talked about with the people they ran into. And so you have a growing awareness among the general community of what these kinds of issues are and what kinds of impacts can happen if there is a flu pandemic.”* Another individual felt it was the responsibility of participants to communicate the information to others: *“I’m responsible for taking opportunities to learn more about this.... I’m also responsible for sharing information with family and friends.”*

Several people wanted a feedback loop instituted so they could track how decisions were being made about pandemic plan components. They asked for copies of documents resulting from the community meetings, websites they could check to see how the plans were being developed, and dates that could serve as milestones in plan development. Participants wanted someone or some entity that assumed accountability for use of the information they offered in the meetings with a *“report card”* issued periodically so they could track progress. Their expectations about how the information would be used by policy makers reflected optimism that the collective voice of local participants would be taken into account when decisions are made about community control measures. There was a general sense that someone in government would receive information from these meetings and use it when they made decisions related to pandemic planning. *“This information needs to get back to Washington immediately, like Monday.”* There was some concern about who the decision makers might be and who could be trusted to make good decisions related to pandemic influenza.

While citizens expected policymakers to take into account public input when making decisions, they were skeptical about whether or not such decisions would be adequately funded or logistically feasible for local governments. They wanted policy makers to know that individuals would be more likely to take responsibility for personal preparedness if accurate, trustworthy information was disseminated early. *“We have more expectations of our government – the government is for the people – we fund the government – but if I want a mask, I better be buying it.”*

Participants at the stakeholder meeting were generally satisfied with the outcomes of the meeting. As stated by one stakeholder: *“I was satisfied in a personal sense that I got to help put my fingerprint, however faint it might be...my thoughts on what might be federal guidelines and I think that’s pretty important.”* However, some stakeholders expressed their belief that other factors may influence the impact that the public engagement process has on policy: *“I do think there are some committed individuals who will use these guidelines to help make policy.... Whether or not those institutions will be able to do that because of politics involved; that remains to be seen. Definitely the people who were there who represented those institutions want to do that, but they don’t work singularly, they work as part of a process, so even though their hearts might be in the right place, there could be other impediments that may not make the actualization of that as fluid and perfect as we like, but that’s the world that we live in.”*

The citizen participants in the stakeholder meeting were more convinced that specific outcomes resulted from the meeting than the stakeholders who viewed the process as a way to share information rather than produce outcomes. There was a broad expectation that policy makers would consider the results of the stakeholder meeting in tandem with the citizen input when making decisions about control measures related to pandemic influenza. This expectation was tempered with some skepticism that decisions would be greatly impacted by this process. *“Ultimately if one or two good ideas come out of this process it’s going to be a homerun. Do I think that this process is going to significantly affect or change policy coming from the CDC and coming from the government – no, I don’t believe it.”* Stakeholders thought that ultimately policy makers would feel more secure in their decisions regarding control measures if they knowingly take citizen input into account when making the decisions.

Chapter 9: Evaluation Results - Impact on Policy

Although further information is needed to determine the extent to which the Public Engagement Project on Community Control Measures for Pandemic Influenza (PEP-CCMPI) influenced Interim Pre-pandemic Planning, indications do exist that PEP-CCMPI was referenced as a source of planning information.

Direct references to PEP-CCMPI

The Interim Pre-pandemic Planning Guidance (IPPG) document issued by the Centers for Disease Control and Prevention (CDC) directly references PEP-CCMPI several times. Other than the CDC, input for developing the IPPG document was received from “Federal agencies, key stakeholders, and partners, including a working group of public health officials and other stakeholders” (p.19). The working group examined data gathered from PEP-CCMPI as one of eight identified sources of information:

- Preliminary statistical analyses of historical data on the implementation of selected NPIs in U.S. cities during the 1918 pandemic.
- Stakeholder input from interagency outreach meetings with public health, private sector, labor unions, faith-based and community partners.
- **Proceedings of community public engagement meetings conducted in five U.S. cities (Atlanta, GA; Lincoln, NE; Seattle, WA; Syracuse, NY; Washington, DC) in October-November 2006.**
- Public opinion poll results conducted by the Harvard School of Public Health in September-October 2006 surveying 1,697 adults in the United States regarding their willingness to follow public health officials’ recommendations for selected pandemic mitigation interventions.
- Peer-reviewed mathematical modeling to assess potential pandemic mitigation interventions during an influenza pandemic.
- Expert opinion of public health officials, including published findings and recommendations of the Committee on Modeling Community Containment for Pandemic Influenza (Institute of Medicine, 2006).
- Preliminary results from a November 2006 Epi-Aid investigation of a seasonal influenza outbreak with associated school closure.
- Preliminary results from review of legal authorities/policies of school closure in each state conducted by the Center for Law and the Public’s Health (p.75).

The PEP-CCMPI itself is discussed at length in the chapter entitled “Assessment of the Public on Feasibility of Implementation and Adherence” (p. 50). In this chapter, the engagement process and its results were described, and it was noted that there was general support for public control measures:

Approximately 95 percent or more of the citizens and stakeholders supported encouraging ill persons to stay at home, and the same high percentage supported canceling large public gatherings and altering work patterns for the purpose of social distancing. A lower percentage (83-84 percent) supported encouraging the members of households with ill persons to stay at home, and a similar percentage favored closing schools and large day care facilities for an extended period....

Although the findings from this poll and public engagement activity reported high levels of willingness to follow pandemic mitigation recommendations, it is uncertain how the public might react when a pandemic occurs. These results need to be interpreted with caution in advance of a severe pandemic that could cause prolonged disruption of daily life and widespread illness in a community. Adherence rates may be higher during the early stages of a pandemic and adherence fatigue may increase in the later stages. These results may not be able to predict how the public would respond to a severe pandemic in their community nor predict how the public will tolerate measures that must be sustained for several months. (p. 50)

The IPPG document does not discuss the extent to which the PEP-CCMPI influenced interim planning guidelines. Nor was PEP-CCMPI cited as evidence to support the implementation of specific control measures. As documented in the above quote, PEP-CCMPI was cited to show the extent to which the public might support specific control measures, with caveats.

References to other sources

When assessing the influence of PEP-CCMPI on Interim Pre-pandemic Planning, instances in which other sources of information are identified as references in the IPPG document **in the absence of** reference to PEP-CCMPI should be noted. For example, the introduction of the IPPG document states that:

Decisions about what tools should be used during a pandemic should be based on the observed severity of the event, its impact on specific subpopulations, the expected benefit of the interventions, the feasibility of success in modern society, the direct and indirect costs, and the consequences on critical infrastructure, healthcare delivery, and society. (p. 19)

...[p]lanning for use of these [non-pharmaceutical interventions] is based on the Pandemic Severity Index, which may allow more appropriate matching of the interventions to the magnitude of the pandemic. (p. 35)

The IPPG document contains references to 108 individual sources, one of which is PEP-CCMPI. The majority of the 108 references are to peer-reviewed journal articles. Throughout the CDC document, journal articles and the other identified sources of information used by the interim guidelines' planners serve as the bulk of supporting references for specific proposed control measures without reference to PEPCCMPI. It may be that the primary purpose of the Report is to establish the technical soundness of the community control measures rather than public acceptability, thereby explaining the emphasis on technical reports.

The PEP-CCMPI reference is cited one time in the document's main narrative – in the chapter entitled “Assessment of the Public on Feasibility of Implementation and Adherence” (p. 50). In contrast, the other primary source of public input referenced by the IPPG document is the Harvard School of Public Health survey on “Pandemic Influenza and the Public.” The Harvard study is cited four times for survey results (pp. 49, 53, 54, 55).

Coinciding influences

There are numerous instances in the IPPG document in which stated guidance **aligns with** the thirteen priority recommendations from PEP-CCMPI, but **does not explicitly state** that the source of such guidance was PEP-CCMPI itself.

For example, the Introduction notes that:

Federal, State, local, territorial, and tribal governments and the private sector all have important and interdependent roles in preparing for, responding to, and recovering from a pandemic. To maintain public confidence and to enlist the support of private citizens in disease mitigation efforts, public officials at all levels of government must provide unambiguous and consistent guidance that is useful for planning and can assist all segments of society to recognize and understand the degree to which their collective actions will shape the course of a pandemic. (pp. 20-21)

This language aligns with priority recommendations one, two, and 11, but there is no direct reference to the priority recommendations or to PEP-CCMPI itself.

In the chapter entitled “Critical Issues for the Use of Nonpharmaceutical Interventions,” the IPPG document states that:

A number of outstanding issues should be addressed to optimize the planning for use of these measures. These issues include the establishment of sensitive and timely surveillance, the planning and conducting of multi-level exercises to evaluate the feasibility of implementation, and the identification and establishment of appropriate monitoring and evaluation systems. Policy guidance in development regarding the use of antiviral medications for prophylaxis, community and workplace-specific use of personal protective equipment, and safe home management of ill persons must be fast-tracked and prioritized as part of future versions of the overall community mitigation strategy. As well, developing appropriate and effective risk communication content and a means for its effective delivery, soliciting active community support and involvement in strategic planning decisions, and assisting individuals and families in identifying their own preparedness needs are critical community factors in achieving success. (p. 47)

This statement and the remainder of the chapter identify a number of general points necessary for

Dated February 2007. Available at http://www.pandemicflu.gov/plan/community/community_mitigation.pdf.

effective implementation of community controls. It is unclear to what extent information generated from PEP-CCMPI was relevant to these overall considerations.

Finally, the IPPG document appendices include planning guides for influenza mitigation directed to 1) businesses and other employers; 2) childcare programs; 3) elementary and secondary schools; 4) colleges and universities; 5) faith and community organizations; and 6) individuals and families. It should be noted that a number of the priority PEP-CCMPI recommendations advocate for high profile educational and informational campaigns to prepare civil entities for a pandemic. The planning guides offer specific recommendations for preparation activities. However, it is again not stated if the creation or inclusion of these planning guides was related to PEP-CCMPI.

It should be noted that evaluating the impact of PEP-CCMPI is difficult at this time because the Pre-Pandemic Planning Guidance Report is an interim report that produced guidance rather than specific recommendations. Although the report makes reference to the PEP-CCMPI, it did not explicitly adopt the 13 recommendations from the public engagement process. Furthermore, the Report indicates it will be updated as new information is obtained. Further evaluation is necessary to determine the impact of PEP-CCMPI on policy: first, the evaluators intend to conduct individual interviews with policy makers to examine how PEP-CCMPI was considered, and second, we will continue to review documents, such as final guidance or recommendations, if and when they are issued.

Chapter 10: Conclusions

In conclusion, the Public Engagement Process on Community Control Measures for Pandemic Influenza met its major goals. Organizers were successful in recruiting citizens to attend the four state meetings. Although none reached the target of attracting 100 citizens, each state site met its goal of having enough citizens to engage in meaningful small and large group discussions. This level of participation was impressive since citizens gave up nearly a full Saturday for the engagement process and were not compensated.

Citizen participants reflected a diversity of demographic characteristic, but did not precisely reflect the demographic characteristics of the broader populations of the four communities (participants tended to be older, higher income, female, and less ethnically diverse than the general population of those communities). Participants were in general agreement that the citizens participating in the meetings represented a diversity of perspectives and expressed a variety of views.

Citizens were generally motivated to participate in the meetings by civic responsibility and an interest in the subject matter. Respondents provided recommendations for broader recruitment including more advanced notices of the meetings, holding the meetings on days other than Saturday, advertising through alternative sources, and enlisting the assistance of various groups likely to have credibility with disenfranchised citizens. Based on experience in other public engagement processes, it is likely that the number of participants and the diversity would increase if citizens were paid a modest stipend.

The public engagement process resulted in increased knowledge about pandemic influenza and community control measures for both stakeholders and citizens. The citizens and stakeholders had sufficient knowledge to engage in informed discussion and to weigh pros and cons regarding community control measures. Although the presentations about pandemic influenza were substantially different across the different meetings, they all appear to have been effective in imparting information necessary for the dialogue. Both groups believed they had sufficient knowledge to engage in informed discussion and the presentations across sites were highly regarded. Potential improvements suggested by participants include more experiential or interactive learning techniques.

The process of knowledge acquisition and dialogue resulted in changes in the beliefs of citizens and stakeholders about values and the acceptability of and compliance with community control measures. Many of the control measures such as cancelling large gatherings, isolating ill persons and encouraging alternative work locations became more acceptable after citizens engaged in deliberations; in addition, citizens tended to agree with each other more after going through the process. These results indicate that there is value to obtaining input from citizens and stakeholders through a dialogic process, beyond information that could be obtained through public polling or opinion surveys. Participants who understand the issues and engage in deliberations about those issues have different beliefs than individuals who do not participate in this type of process. It is interesting that although there was significant change in beliefs, the participants themselves perceived little change. Citizens and stakeholders felt the process helped them frame the issues and consider other points of view, but thought their own ideas did not change substantially.

Citizens and stakeholders were more likely to believe local and state health departments should make decisions about community control measures rather than other levels of government or individuals themselves. The majority of stakeholders and citizens thought community control measures should be mandatory rather than voluntary. As with opinions about acceptability and compliance with community

control measures, opinions about who should make decisions about these measures also changed as a result of the process. After deliberations, participants were more likely to believe local units of government should make decisions about community control measures, and although, a majority believed these measures should be mandatory rather than voluntary, participants were more likely to favor voluntary compliance after the process. These results further the conclusion that obtaining input from citizens and stakeholders who are informed and engage in dialogue yields different results than surveys and polling.

With only minor regional differences, citizens and stakeholders thought the process was of high quality. For example, citizens and stakeholders thought participants felt comfortable talking in the meeting, the discussion was fair to all participants, and the process helped them understand the types of trade-offs involved in implementing community control measures. Although observers noted substantial process differences across citizen meetings and across small group facilitators within each meeting, the overall public engagement process was successful in producing a high quality deliberative procedure from the perspective of the participants. There were mixed reviews about the inclusion of electronic polling as part of the process. Some found it valuable, while others thought it detracted from the process, taking time away from deliberation and discussion.

Stakeholders had high regard for the work of the citizen groups and reported incorporating citizen input into their discussions. Both groups appeared satisfied with the process and thought the input would be seriously considered by decision makers in establishing public policy regarding community control measures for pandemic influenza. At this point it is difficult to determine what impact the public engagement process had on official policy. However this process was discussed as a source of input along with many others in the federal report, “Interim Pre-Pandemic Planning Guidance: Community Strategy for Pandemic Influenza Mitigation in the U.S.” (<http://www.pandemicflu.gov/plan/community/commmitigation.html>). At this point it is difficult to identify how the results from the public engagement process were considered or their relative impact in comparison to other sources of input. The 13 recommendations from the public engagement process were not explicitly adopted in the Guidance Report; however, the Report was framed as preliminary guidance rather than final recommendations. Further efforts are required to determine how policy makers used the input from the public engagement process and how they might consider it in the future.

Appendix 1 Sample of Post Meeting Survey

Public Engagement on Community Control Measures Against 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 evaluation, 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

| Your Confidential ID Number | | | | | | | |
|-----------------------------|---|--|--|---|--|--|--|
| 1 | 9 | | | | | | |
| Your Year of Birth | | | | Last Four Digits of Your Home Phone Number | | | |

Section I: Knowledge about Pandemic Influenza (Flu)
We are interested in what you know right now about influenza.

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

1. How soon after someone is infected with an influenza virus will they get sick?
 - ☐ Almost immediately after they are infected
 - ☐ Within 24 hours after infected
 - ☐ A few weeks after they are infected
 - ☐ About a month after they are infected
 - ☐ Don't know
2. When will the next pandemic occur?
 - ☐ During the next year
 - ☐ Within the next 5 (five) years
 - ☐ Within the next 30 (thirty) years
 - ☐ No one can predict when it will occur
 - ☐ Don't know
3. About how many people do you think die in a typical year from flu in the United States?
 - ☐ 6,000
 - ☐ 36,000
 - ☐ 156,000
 - ☐ 256,000
 - ☐ Don't know
4. Who is at risk when a new influenza virus appears that has never been seen before?
 - ☐ The entire population of the world is susceptible
 - ☐ Only children are at risk
 - ☐ Only people in the country that the virus is first discovered in are at risk
 - ☐ Only people who have never gotten a flu shot are at risk
 - ☐ Don't know
5. How many pandemics have occurred over the last 100 years?
 - ☐ 0 (none)
 - ☐ 4 (four)
 - ☐ 20 (twenty)
 - ☐ 35 (thirty-five)
 - ☐ Don't know
6. 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
7. About how many people could become ill in the United States during a severe pandemic?
- ☐ 1 million
 - ☐ 20 million
 - ☐ 90 million
 - ☐ 200 million
 - ☐ Don't know
8. Which of the following is not considered a viable option to control the spread of flu during a pandemic?
- ☐ Closing schools and daycares
 - ☐ Closing all retail outlets like grocery stores and shopping malls
 - ☐ Isolating sick people in their homes
 - ☐ Canceling mass gatherings like church and sporting events
 - ☐ Changing people's work schedules and locations
 - ☐ Don't know

Section II: Opinions about Influenza Community Control Measures

We are interested in your personal opinions about control measures in the event of an influenza pandemic.

- 9 Imagine you are in a position to recommend to policy makers the most important values to consider when making decisions about control measures for an influenza outbreak. 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 “5” 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 5 (again, where 1 is ‘Most Important’ and 5 is ‘Least Important’). You can use all numbers, including 1 and 5, more than once.

| SOCIAL VALUE | Most Important | | | | Least Important |
|---|----------------|---|---|---|-----------------|
| Freedom – Policies should not infringe on personal freedoms of individuals to congregate, travel, or work. | 1 | 2 | 3 | 4 | 5 |
| Safety & Security – Ensuring public health and safety is a priority in the event of an influenza pandemic. | 1 | 2 | 3 | 4 | 5 |
| Equality – Everyone is treated equally. | 1 | 2 | 3 | 4 | 5 |
| Respect for Life – Policies should ensure that everyone has the best chance of survival after getting influenza. | 1 | 2 | 3 | 4 | 5 |
| Prosperity – Policies should retain everyone’s right to work as much as they want to meet their needs. | 1 | 2 | 3 | 4 | 5 |
| Personal Growth – Policies should maintain learning opportunities and experiences for young persons. | 1 | 2 | 3 | 4 | 5 |
| Utilitarian – Policies should ensure the greatest good for the greatest number of people. | 1 | 2 | 3 | 4 | 5 |
| Social Order – Policies should minimize the risk of chaos in the event of an influenza pandemic. | 1 | 2 | 3 | 4 | 5 |
| Responsibility – Individuals and communities should be expected to do what is needed to make sure that the disease does not get a foothold. | 1 | 2 | 3 | 4 | 5 |
| Independence – Allowing individuals to make their own decisions about what is best for them and their family without government restrictions should be a priority. | 1 | 2 | 3 | 4 | 5 |

10. In the event of an influenza pandemic, in your opinion how **acceptable** are the following control measures for **your community**?

| Community Control Measure | Very Acceptable | Somewhat Acceptable | Neutral | Somewhat Unacceptable | Very Unacceptable |
|--|-----------------|---------------------|---------|-----------------------|-------------------|
| Closing schools from grades K-12 | 1 | 2 | 3 | 4 | 5 |
| Encouraging businesses to promote telecommuting (working from home using computers and telecommunications) | 1 | 2 | 3 | 4 | 5 |
| Closing day care centers | 1 | 2 | 3 | 4 | 5 |
| Encouraging businesses to use alternative work locations | 1 | 2 | 3 | 4 | 5 |
| Canceling events where large groups of persons are expected to gather | 1 | 2 | 3 | 4 | 5 |
| Requiring all people in households with ill persons to stay home for up to 7 days | 1 | 2 | 3 | 4 | 5 |
| Not allowing children to congregate outside of schools and day care settings | 1 | 2 | 3 | 4 | 5 |
| Encouraging businesses to adopt flexible work schedules | 1 | 2 | 3 | 4 | 5 |
| Isolation of ill persons at home if hospitalization is not required | 1 | 2 | 3 | 4 | 5 |

11. If the following control measures were used in the event of an influenza pandemic, **how likely would you be to comply** with each? (If a control measure does not apply to you, such as if you do not have children in school, please mark "not applicable").

| Individual Activity for Community Control Measures | Very Likely | Somewhat Likely | Neutral | Somewhat Unlikely | Very Unlikely | Not Applicable |
|--|-------------|-----------------|---------|-------------------|---------------|----------------|
| Keeping your child home from school | 1 | 2 | 3 | 4 | 5 | |
| Working from home instead of going in to work | 1 | 2 | 3 | 4 | 5 | |
| Keeping your child home from day care | 1 | 2 | 3 | 4 | 5 | |
| Using alternative work locations to conduct your work | 1 | 2 | 3 | 4 | 5 | |
| Not attending events where large groups of persons are expected to gather | 1 | 2 | 3 | 4 | 5 | |
| Staying home for up to 7 days if you had contact with an ill person in your home | 1 | 2 | 3 | 4 | 5 | |
| Keeping your child from meeting other children outside of school or day care | 1 | 2 | 3 | 4 | 5 | |
| Taking advantage of a flexible work schedule | 1 | 2 | 3 | 4 | 5 | |
| Staying at home if you are ill and if hospitalization is not required | 1 | 2 | 3 | 4 | 5 | |

12. In the event of an influenza pandemic, who should determine what control measures are adopted or required? Please check only one box.

☐ Individuals themselves
☐ Local health department
☐ City or county government
☐ State Health Department
☐ State government
☐ Federal government

13. In the event of an influenza pandemic, which of the following statements do you agree with most about control measures? Control measures should be... Please check only one box

☐ Voluntary – People themselves should decide whether to comply with control measures.
☐ Mandatory – All people should be required to comply with control measures.

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.

14 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 circling the appropriate number.

| Statement | Agree Strongly | Agree Somewhat | Neither Agree nor Disagree | Disagree Somewhat | Disagree Strongly |
|--|----------------|----------------|----------------------------|-------------------|-------------------|
| I think this process has produced credible, relevant and independent information. | 1 | 2 | 3 | 4 | 5 |
| I think officials will use our input in their decisions about how to use community control measures. | 1 | 2 | 3 | 4 | 5 |
| One person or a small group of people dominated the discussion. | 1 | 2 | 3 | 4 | 5 |
| I felt comfortable talking in this discussion. | 1 | 2 | 3 | 4 | 5 |
| I think I have enough information right now to have a well-informed opinion about implementing community control measures in a pandemic. | 1 | 2 | 3 | 4 | 5 |
| I think other people in this discussion felt comfortable talking. | 1 | 2 | 3 | 4 | 5 |
| This discussion was fair to all participants. | 1 | 2 | 3 | 4 | 5 |
| I think this process produced a valuable outcome regarding community control measures. | 1 | 2 | 3 | 4 | 5 |
| I think participants at this meeting represented a broad diversity of perspectives | 1 | 2 | 3 | 4 | 5 |
| Important points or perspectives were left out of the day's discussion. | 1 | 2 | 3 | 4 | 5 |
| I think this process will increase the public's support of the decision ultimately made on how to use community control measures. | 1 | 2 | 3 | 4 | 5 |
| I think this process helped me better understand the types of trade-offs involved in using community control measures. | 1 | 2 | 3 | 4 | 5 |

Please use the blank space on the next page to add any additional comments:

Comments:**Section IV: Questions about You**

Now we need some information about you. On the last two pages of this survey there are questions about you. Please remember that the information you provide in this survey is anonymous and won't be linked back to you personally.

15 What is your gender? Please check only one

- ☐ Male
- ☐ Female

16. What is the highest level of education you have completed? Please check only one

- ☐ Less than high school
- ☐ Some high school
- ☐ High school graduate
- ☐ Some college
- ☐ College graduate
- ☐ Some graduate school
- ☐ Graduate school graduate

17. In which of the following categories is your age? Please check only one

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

18. What is your race or ethnicity? Please check only one

- ☐ Hispanic White
- ☐ Hispanic Black
- ☐ Non-Hispanic White
- ☐ Non-Hispanic Black
- ☐ Asian
- ☐ Native American
- ☐ Other [PLEASE SPECIFY] _____

19. What is your annual household income level? Please check only one

- ☐ \$15,000 or less
- ☐ \$15,001 - \$30,000
- ☐ \$30,001 - \$60,000
- ☐ \$60,001 - \$100,000
- ☐ \$100,001 or more

20. Do you have minor children at home? Check all that apply

- ☐ Yes, I have children five years of age or under
- ☐ Yes, I have children from ages 6 – 18
- ☐ No, I have no children at home

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