



**AT-RISK POPULATIONS PROJECT
ENGAGEMENT MEETINGS:
FINAL REPORT**

SEPTEMBER 2008

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I. Executive Summary

Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), the Association of State and Territorial Health Officials (ASTHO) worked with state, local, and territorial health agencies, federal entities, and other key stakeholders to develop model planning guidance on at-risk populations and pandemic influenza. ASTHO's goal was to develop sound, evidence-based guidance on planning for at-risk populations during an influenza pandemic.

ASTHO used a multifaceted strategy to achieve this goal. An advisory panel directed the guidance development; a comprehensive literature search was conducted to understand current planning and best practices in this area; subject matter expert-based work groups were formed to research and draft the guidance document; and at-risk individuals and national stakeholders were engaged to provide key input. This report is a comprehensive summary of the engagement meetings that occurred in March 2008.

Three engagement meetings were held. The first public meeting was March 8, 2008, at the Boston University School of Medicine and included 57 members of Massachusetts' at-risk population. The second public meeting was March 15, 2008, at the South-Broadland Presbyterian Church in Kansas City, MO, and included 66 participants. Finally, a national stakeholders' meeting (NSM) took place March 20, 2008, in Washington, DC with 21 representatives from federal, state, and territorial agencies, as well as community and faith-based organizations. Overall, participants were fairly diverse in terms of age, gender, and ethnicity, although there was relatively little representation from the Hispanic community and less from the Asian community or persons in the 18-30 age range. Participants also represented a diversity of at-risk factors. Greater diversity could have been achieved had more guardians of children and English-as-a-second language speakers attended the public meetings. Although many non-family member caretakers of at-risk individuals were present, the process may also have benefited from more representation of those whose family members have a disability.

Each meeting followed a similar structure. Participants first listened to presentations by federal, state, and local public health officers on pandemic influenza and what may occur during a pandemic. (Stakeholders also heard an overview of key themes and ideas from the two previously held public meetings.) Participants then met in small groups of up to 10 participants with a facilitator and note-taker to discuss the definition of at-risk populations, identify their unique needs, and recommend ways to meet these needs. Finally, each group proposed two to three specific recommendations on issues to be considered in the guidance, which became part of a ballot subsequently used to poll participants, with responses based on a five-point Likert scale.

Participants at the NSM and Kansas City meetings responded to two baseline questions designed to obtain general reactions to the definition of at-risk populations drafted by the Advisory Panel. A majority of Kansas City participants agreed with the definition provided - that the six factors presented reflect the most vulnerable populations they know. A majority of stakeholders also agreed that the factors presented reflect the most vulnerable populations they know, but were split in their agreement with the workgroup definition.

Participants also responded to questions developed in the table groupings at all three meetings. Tables proposed a total of 42 issues. These "pollable" issues addressed changes in the definition, specific needs of at-risk populations during a pandemic, and potential solutions to these needs (Appendix A). Meeting facilitators presented the issues to participants at the end of each

meeting; participants rated the strength of their agreement with the issues on a scale of one to five. Meeting facilitators then tabulated the responses to reflect the group's overall agreement. Participants proposed being more specific with wording of the definition overall, clarifying or omitting the term "discrimination," adding the term "mental health," and changing the category "limited language competency," which some considered objectionable terminology. They also suggested adding children and undocumented residents to the definition. Specific needs identified by participants were in the areas of communication, health care, economics, transportation, and food and supplies. Kansas City participants also identified needs in the area of utilities, while stakeholders voiced concern over population movement and implementation. Suggested solutions identified by participants were in the areas of communication, community preparedness, health care, personal preparedness, and economics. Participants in Boston offered a solution for bringing food and supplies to at-risk populations.

At the conclusion of the meetings in Boston and at the NSM, participants discussed the experience in a focus group,¹ while facilitators and note-takers at all meetings offered their reflections in a post-meeting debriefing. Focus group participants agreed that the best part of the day was the information they received and the chance to learn from and talk with others. Boston participants commented that they appreciated being consulted about at-risk pandemic planning. Both groups felt that they gained more knowledge as a result of the day.

When asked what could be improved, participants in Boston suggested simplifying the agenda because some participants may have suffered from "information overload and exhaustion." NSM focus group participants suggested that bringing more visibility to the event would have increased its impact. Both groups stressed that inclusion, preparation, and coordination should be guiding ideals when working with at-risk populations. Overall, the project met its goals and provided many insights into public engagement with at-risk individuals. Although participants' responses to questions asked at each meeting represent only a limited snapshot of the opinions of small groups of people, those responses were considered in addition to the rich discussions that were captured by notetakers at each table. That input was subsequently incorporated as appropriate and relevant into the guidance document, *At-Risk Populations and Pandemic Influenza: Planning Guidance for State, Territorial, Tribal, and Local Health Departments*.

II. The Community Engagement Process

The At-Risk Populations Project engagement meetings were coordinated by ASTHO and The Keystone Center, with collaboration from the National Association of County and City Health Officials (NACCHO), the Center for Infectious Disease Research and Policy (CIDRAP), CDC, and several state and local agencies and organizations. A complete listing of participating organizations can be found in Appendix B. During this series of two public and one national stakeholders' engagement meetings, the framework for draft guidance was presented and discussed. The goals of the engagements were to: 1) assess community values as they relate to vulnerable population needs during an influenza pandemic; 2) gather public input on what should be included in draft guidance on assisting at-risk populations during a pandemic; and 3) obtain

¹ At all meetings the participants were asked to volunteer after the meetings for a focus group to share feedback on the meeting process, what worked, and what could be changed to make these sessions more effective. At the Kansas City public meeting, no one volunteered to remain after and share their thoughts on the process.

public feedback on what will and will not work in their community during a pandemic, as well as suggestions for changes that may be necessary to existing systems to make at-risk populations more accessible, prepared, and educated prior to any pandemic outbreak.

Public meeting participants were identified based on a definition of at-risk populations developed by the ASTHO At-Risk Populations Project Advisory Panel. NSM participants were selected by identifying the agencies and organizations that work with these individuals. The definition of at-risk considered factors that increase an individual's susceptibility to the impacts of an influenza pandemic, particularly when systems become progressively overloaded during moderate and severe pandemics. These six factors were:

- Economic disadvantage
- Social, cultural, or geographical isolation
- Particular susceptibility to injury or death because of physical, cognitive, or sensory disability or disease susceptibility, whether chronic or emergent
- Limited language competency²
- Limited access to services because of discrimination
- Unaccompanied people (e.g., homeless, aged people living alone, and travelers)

This definition also provided the basis for discussion at each engagement meeting. The definition was changed as a result of the public engagement process, so it is important to note that the definition above is not the definition included in the national guidance. This change reflects the importance of obtaining public input to create public policy at the earliest opportunity.

III. Methods

Each of the three meetings consisted of three fundamental components (agendas are located in Appendix C). Federal, state, and local public health officials shared information to educate participants on pandemic influenza and what may occur during a pandemic. The first presentation discussed the basics of influenza; how it is spread; differences between seasonal, avian, and pandemic influenza; government's plans for fighting pandemic influenza; and actions people can take to prepare. The second presentation discussed who is most at-risk; what could happen during a pandemic; the process for collecting public input; the purpose of the guidance; and current state and local health agency planning activities. Question-and-answer sessions followed all presentations, and experts noted the questions were sophisticated, reflecting an understanding of the complexities of addressing pandemic influenza.

In addition to these presentations, NSM participants heard a brief summary of the results from the two public meetings. A representative from Boston and one from Kansas City provided an overview of major themes and an assessment of the impact of the meeting on the individuals and community. The goal of these presentations was to provide the stakeholders with a sampling of public responses, concerns, and solutions on the guidance for at-risk populations.

After the presentations, participants at each meeting met in small groups. They discussed the proposed definition of at-risk populations with the aid of four questions:

² The wording of this factor was changed based on participant feedback from the first meeting held in Boston, where participants found the wording of the factor as "limited language competency" objectionable. "Limited language skills" was the terminology used for the Kansas City public meeting and the NSM in Washington. DC.

1. Do you support the definition as written? Why or why not?
2. Are there more people that should be included in the definition?
3. Are there people who should not be included on this list?
4. Are there other ways that you think the definition should be changed?

Participants also discussed specific needs of those populations during a pandemic, and potential solutions to these needs, with the aid of four questions:³

1. What help would at-risk populations need during a pandemic (food, rides to a doctor, in-home assistance, etc.)?
2. Imagine a severe flu pandemic in [city]. What needs to happen so that at-risk people get the healthcare and emergency support they will need?
3. What might prevent at-risk people from getting needed care and services during a flu pandemic?
4. What are your table's top two or three recommendations to make sure the [city] community is providing needed care and services to at-risk populations during a flu pandemic?

At all meetings, participants were asked to document questions or comments they had during the discussions that were not on the immediate topic on note-cards (These “parking lot” issues are transcribed in Appendix D).

Discussions were facilitated chiefly in English; however, one table in Boston included sign language interpreters using American Sign Language for deaf participants, and Kansas City included a table with Spanish-speaking participants and interpreters.

Following the discussions, tables proposed suggestions to ensure at-risk populations have needed care and services during a pandemic. Suggestions were collected and written in a pollable format (e.g., “Do you agree or disagree...”). Participants were polled using a five-point Likert scale to gather a sense of the groups’ priorities and needs (complete listings of polling results are located in Appendix A). After the polling, facilitators and note-takers participated in a debriefing session while a small group of participants joined in a focus group (in Boston and at the NSM).

Although participants’ responses to questions asked at each meeting represent only a limited snapshot of the opinions of small groups of people, those responses were considered in addition to the rich discussions that were captured by notetakers at each table. That input was subsequently incorporated as appropriate and relevant into the guidance document, *At-Risk Populations and Pandemic Influenza: Planning Guidance for State, Territorial, Tribal, and Local Health Departments*.

³ The specific wording of the second set of questions changed for the Kansas City meeting and the NSM due to the suggestion from Boston facilitators and note-takers to use questions phrased in “plain English.” The exact questions discussed at the Kansas City meeting and NSM were: 1. What help would you need during a pandemic (such as help getting food, rides to a doctor, or in-home assistance)? 2. Imagine a severe flu pandemic is in this city. What healthcare and emergency support will at-risk populations need? Who needs to make sure those populations get the needed support? 3. What public or private services do you use that at-risk populations in your community may need during a pandemic? 4. What might prevent at-risk people from getting needed care and services during a flu pandemic? 5. What are your best suggestions to make sure this city provides needed care and services to at-risk populations during a flu pandemic?

IV. Results

The first of two public meetings was held on March 8, 2008, at the Boston University School of Medicine and included 57 members of Massachusetts' at-risk population. The second public meeting was held on March 15, 2008, at the South-Broadland Presbyterian Church and included 66 members of Kansas City's at-risk population. The NSM was held on March 20, 2008, in Washington, DC, and consisted of 21 representatives from federal, state, and territorial agencies; and community and faith-based organizations.

A. Demographics

Public participants completed demographic questionnaires as part of meeting registration. They were asked questions regarding age, gender, and ethnicity; if they were a parent or guardian of a child 18 years of age or younger; if they spoke a first language other than English; and if they or a family member had a disability or impairment. Below is a comparison of answers by city:

Table 1: Participant demographic information⁴

	Boston	Kansas City
Age		
18-30	4%	13%
31-50	40%	51%
51 and above	56%	36%
Sex		
Male	32%	51%
Female	68%	49%
Ethnicity*		
Asian	1%	2%
Black (African-American)	29%	63%
Hispanic or Latino	4%	9%
White	63%	26%
Other	4%	3%
Parent or guardian of children 18 years or younger?		
Yes	21%	26%
No	79%	74%
Speak a first language other than English?		
Yes	13%	15%
No	85%	85%

⁴ Results for questions identified with an asterisk equal more than 100% because some participants had more than one response for these questions.

Table 2: Participant information regarding disabilities

	Boston	Kansas City
Disability or impairment?*		
Yes	57%	36%
No	43%	64%
Is the disability related to:*		
Mobility	47%	14%
Vision	16%	3%
Hearing	19%	0%
Cognitive Ability	12%	8%
Mental Health	9%	25%
Chronic Disease	26%	31%
Other	35%	17%
Family member with a disability or impairment?		
Yes	31%	33%
No	69%	67%
Is the disability related to:*		
Mobility	36%	30%
Vision	24%	3%
Hearing	28%	6%
Cognitive Ability	44%	9%
Mental Health	20%	24%
Chronic Disease	8%	45%
Other	35%	18%

Participants in Boston generally represented an older, white female population with the majority being at risk due to mobility, chronic disease, and other issues. Participants in Kansas City generally represented a middle-aged, black male population with the majority not characterizing themselves as being at-risk. Of those that were at risk, the majority had chronic disease, mobility, mental health, and other issues, such as homelessness. Overall, participants in both meetings were fairly diverse in terms of age, gender, and race. The majority of participants from both communities spoke English as their first language. Fewer than one-third were parents or guardians of children under 18. These factors are reflected in the definition of the populations that are at increased risk during a pandemic.

B. Polling Results on Baseline Questions⁵

Kansas City and NSM participants first responded to a series of “baseline” questions prepared in advance of the meetings. The goal of these questions was to obtain a general reaction to the definition of at-risk populations developed by the Advisory Panel. These questions were not asked in Boston. Responses to these baseline questions are tabulated below.⁶

Table 3: Responses to baseline question 1

Do you agree/disagree with the proposed definition (6 factors) as written?		
	Kansas City	NSM
Agree	51%	40%
Disagree	28%	40%

A slight majority of participants at the Kansas City meeting supported the definition as written. Reasons for disagreement may include concern over certain terms, such as “discrimination,” and the feeling that some groups had been excluded. The stakeholders were split on their agreement with the definition, noting that the guidance should move away from dichotomous definitions of risk (i.e., people are either “at risk” or “not at risk”); risk should instead be considered on a continuum. They felt that the factors identified seemed too general and were overly inclusive, and that it may be better to define people based on functional ability.

⁵ Polling results on baseline questions, suggested changes to the definition, needs and concerns, and solutions were calculated as follows:

- 1) Boston meeting: A total of 57 participants attended the Boston meeting. Polling was conducted orally and transcribed at each table. Respondents were asked to give an answer on a Likert scale, and 57 respondents (100% of attendees) replied with an answer to each of the 15 questions.
- 2) Kansas City meeting: A total of 66 participants attended the Kansas City meeting. Forty-seven attendees who participated in the polling session at the end of the day responded to each of the 18 questions. Polling was conducted orally and transcribed at each table, and respondents chose responses from a Likert scale.
- 3) National Stakeholders meeting: A total of 21 participants attended the National Stakeholders meeting. Participants associated with a Federal agency were asked to complete a separate ballot (results not included in this report). Between 13 and 16 people responded to each question.

Polling was conducted on a written ballot, and results were tallied after the meeting. Percentages of respondents who agreed with a statement were calculated by combining numbers in the “Strongly Agree” and “Agree” categories and dividing that number by the total number of respondents for the individual question. Percentages of respondents who disagreed with a statement were calculated by combining numbers in the “Do Not Agree” and “Disagree” categories and dividing that number by the total number of respondents for the individual question. “Neutral” answers were not considered to be part of either the “Agree” or “Disagree” category, but “Neutral” answers were considered as part of the overall question tally. All responses to the 15 questions asked at the Boston meeting and the 18 questions asked at the Kansas City meeting had a consistent total (N=57 and N=47, respectively). The responses to the 13 questions asked at the National Stakeholders Meeting had varying totals (from N=13 to N=16), and each percentage was evaluated with respect to the total from the individual question.

⁶ Where the percentages do not equal 100, it reflects that either all participants did not vote, or some were neutral. The choices for polling were based on a 5-point Likert scale made up of: 1) strongly agree; 2) agree; 3) neutral; 4) disagree; 5) strongly disagree.

An additional factor that could have caused the split was the introduction of another definition of at-risk populations drafted by the Department of Health and Human Services (HHS). While the HHS definition was introduced at the NSM to provide context for how to best link the two concepts, the introduction of this definition created concern over having different definitions for at-risk populations. Participants questioned “what kind of confusion will it cause?” and “will this be workable?” They suggested that there needs to be a universal definition. To help reduce confusion, and to create cohesion between the two definitions, the HHS definition was included in the guidance document along with the definition developed as part of this project. Context for how the two definitions interrelate was also included.

Table 4: Responses to baseline question 2

Do you agree/disagree that these factors include the most vulnerable populations you know?		
	Kansas City	NSM
Agree	68%	77%
Disagree	19%	23%

Participants at both the Kansas City meeting and the NSM strongly agreed that the factors in the definition developed by the Advisory Panel include the most vulnerable populations.

C. Polling Results on Suggested Changes to the Definition

Participants at all three meetings made many suggestions about how to change the definition of at-risk populations to make it clearer, more precise and more understandable. Suggested changes focused on the categories of discrimination, mental health, children, undocumented residents, public infrastructure workers, and those at increased risk of infection.

Table 5: Responses on the topic of discrimination

	Agree	Disagree
Discrimination should be defined as an overarching attribute instead of within bullet point because of the scope of this document. (NSM)	60%	27%

One significant area of discussion involved the word “discrimination” in the definition. Many expressed concern over its meaning, but did not propose changes to the term. Participants in both Kansas City and Boston suggested making it more specific. Stakeholders responded to this concern by proposing a change. During the meeting, 60% agreed that because discrimination is an issue within all of the six factors listed, it should be listed as an overarching attribute instead of a specific factor. They felt that listing it separately might make the definition redundant.

Another significant area of discussion involved the terms “limited language competency” in the at-risk definition. Although no pollable questions were offered on how to modify this term, a large number of discussion groups at all meetings addressed the factor. Initially, the factor was titled “limited language competency” in Boston; however, many participants felt this was objectionable. One table suggested using “limited language and cultural proficiency.” Another suggested changing it to “communication barriers.” Others proposed that the category should be expanded with examples. Before the Kansas City meeting, the factor was changed to “limited language skills.” Yet, participants at this meeting still noted that “limited language skills” did not capture the full gamut of communication, such as nonverbal and symbolic methods. They also remarked that this section should include communication disorders or problems. Aware of the

concerns public participants had with the terminology, many tables at the NSM discussed the topic. One group suggested replacing “limited language skills” with “limited English proficiency.” The term was ultimately changed in the guidance to “Trouble reading, speaking, or understanding English.”

Table 6: Responses on the topic of mental health

	Agree	Disagree
Mental health should be named specifically as an “at-risk population.” (<i>Boston</i>)	72%	21%

A third significant area of discussion involved the phrase “mental health”. Participants at both public meetings did not recognize that mental health was intended to be included in the factor “particular susceptibility to injury or death because of physical, cognitive, or sensory disability or disease susceptibility, whether chronic or emergent.” For this reason, 72% of participants in Boston agreed that mental health should be named specifically as an at-risk population.

Participants in Kansas City also noted that depressed and stressed people should also be explicitly identified in the definition. The stakeholders made the suggestion of adding mental health after the word “cognitive” as a way to make the definition clearer: “particular susceptibility to injury or death because of physical, cognitive, or sensory disability or disease susceptibility, whether chronic, *mental health*, or emergent.” The definition was changed to “Needing support to be independent in daily activities because of physical disability; developmental disability; mental illness or substance abuse/dependence; difficulty seeing or hearing; or medical conditions” in the guidance as a reflection of the feedback received at the engagement meetings.

Table 7: Responses on the topic of children

	Agree	Disagree
Children should be named in the definition. (<i>Boston</i>)	82%	12%
Children should be added to the examples of “unaccompanied people.” (<i>NSM</i>)	57%	29%

A fourth significant area of discussion involved the position of children in the definition.

Participants in Boston and Kansas City both thought that children should be named specifically in the definition. In Boston, 82% agreed that children should be explicitly identified.

Stakeholders suggested that one way to include children would be to add them to the examples of unaccompanied people. More than half (57%) of stakeholders agreed with this suggestion, noting that they “have different needs than adults” and that many are unaccompanied due to “foster care” situations. The term “some children” was added as an example of people who might not have a support network, putting them at risk of consequences of a pandemic.

Table 8: Responses on the topic of undocumented residents

	Agree	Disagree
Undocumented persons should be included in the planning for pandemic influenza response. (<i>NSM</i>)	93%	7%

A fifth significant area of discussion involved the proposed inclusion of undocumented individuals in the definition. In Kansas City, participants were concerned that hesitations among undocumented workers and residents about being identified may reduce their access to

information and put them at greater risk. Stakeholders addressed the issue with strong agreement (93%) that undocumented persons should be included in the planning for pandemic influenza response. This was considered in the revisions made to the definition after all three meetings.

Table 9: Responses to other suggested changes

	Agree	Disagree
Social isolation puts you at greater risk than geographic or cultural isolation. (<i>Boston</i>)	68%	18%
People who participate in risky behavior (i.e. gang activity or substance abuse) should be included in the definition. (<i>Boston</i>)	11%	58%
People with more than one at-risk factor (i.e. economically disadvantaged and blind) should be specifically mentioned in the definition. (<i>Boston</i>)	33%	36%
Workers who maintain public infrastructure and those who directly aid at-risk persons should be treated first. (<i>Kansas City</i>)	81%	9%
The HHS definition should be adopted in this guidance and the ARPP should be presented to provide further detail. (<i>NSM</i>)	79%	7%

Less frequent areas of discussion regarding the definition involved including the populations of infrastructure employees, those who have more than one at-risk factor, and the uninsured/underinsured in the definition; as well as using the alternative definition proposed by the HHS. Participants in Boston and Kansas City suggested including infrastructure employees in the definition, with 81% agreeing to this suggested change in Boston. Participants in Boston and Kansas City both agreed that some people are more at-risk than others. Boston participants agreed (68%) that social isolation puts people at greater risk than geographic or cultural isolation; however, they disagreed on whether certain populations should be given special treatment. Boston participants were split (33% agree, 31% neutral, 36% disagree) as to whether the definition should explicitly mention people with more than one at-risk factor (e.g., economically disadvantaged and blind) and 58% of respondents there disagreed that people who participate in risky behavior (e.g., gang activity or substance abuse) should be included in the definition. Respondents in Kansas City also agreed that some people were more at-risk than others because of multiple factors, although they did not propose a pollable question on this topic. Finally, participants in both Boston and Kansas City suggested including the uninsured and underinsured.

The stakeholders also suggested adopting the HHS definition, described above.⁷ Reasoning that different definitions of risk have the potential to create confusion, 79% of stakeholders agreed that the HHS definition should be adopted in this guidance and the Advisory Panel's proposed definition should be presented to provide further detail.

D. Polling Results on Needs or Concerns

Participants in all three meetings discussed specific needs and concerns of at-risk populations during a pandemic.

⁷ The HHS definition was not shared at the two community meetings as it was drafted by HHS for a specific purpose different from goals for this project. The factors-based approach was chosen by the Advisory Panel to more precisely identify individuals at-risk of the consequences of a pandemic.

Table 10: Responses by city to communication needs and concerns for at-risk populations during a pandemic

	Agree	Disagree
Existing networks of communication work well enough for relaying information to at-risk populations during a pandemic. (<i>Boston</i>)	2%	86%
You are likely to get information about an emergency from television. (<i>Kansas City</i>)	77%	2%
You know where you can go to get help and information during a pandemic. (<i>Kansas City</i>)	40%	40%

A major concern among all participants was communication. Participants stated that they felt that the availability of information for at-risk individuals is insufficient, that they are unaware where to get information during a pandemic, and that public health messages are often contradictory. In Boston, there was strong disagreement (86%) that existing networks of communication work well enough to relay information during a pandemic. In Kansas City, although 77% agreed that they are likely to get information in an emergency from television, they were split (40% agree, 40% disagree) on knowing where to go to get help and information during a pandemic. Participants at both meetings felt that messages were not designed appropriately for certain at-risk populations, such as the deaf and non-English speaking populations. Stakeholders expressed concern that public health messages regarding pandemic behavior were contradictory. They noted that the government is presently calling for isolation and quarantine in the case of a pandemic, but at the same time telling people to check on their neighbors during an event.

Table 11: Responses by city to health care needs and concerns for at-risk populations during a pandemic

	Agree	Disagree
Discrimination, whether intentional or not, interferes with delivery of important health services. (<i>Kansas City</i>)	81%	9%
You have been adversely affected by needing to go to more than one place to get healthcare services. (<i>Kansas City</i>)	72%	6%
People should not be required to show identification in order to get treatment in a pandemic. (<i>Kansas City</i>)	62%	19%
There should be an alternative to getting medicine from a doctor. (<i>Kansas City</i>)	79%	6%

A second major topic of concern was health care. Public participants were upset over current inequalities in the health care system. In Boston, one table noted that “supposedly if a person with a disability calls 911, they will be helped appropriately, but I’m not sure if that is actually true.” Kansas City participants strongly agreed (81%) that discrimination, whether intentional or not, interferes with delivery of important health services. Almost three-quarters of participants (72%) agreed that they have been adversely affected by needing to go to more than one place to get health care services. During discussions, one participant noted that the current inefficiencies are “maddening.” Another stated that discrimination in the system keeps people from receiving health care, noting that “pride keeps you from going, but your body will let you know.” Participants in Boston also expressed concern over current inefficiencies in the system. Tables noted that “HIPAA keeps everything separate” making “integrating information from different registries” during a pandemic “difficult.” Finally, participants in all cities worried about access to medication and vaccination during a pandemic. In Kansas City, participants agreed (62%) that people should not be required to show identification in order to get treatment in a pandemic. They also strongly agreed (79%) that there should be an alternative to obtaining medicine from a doctor. They were worried that the system would be overrun with daily services and that doctors and medication would be difficult to access in a pandemic. One participant in Boston asked, “How do we get medications in a case when pharmacies are closed out?” Stakeholders reiterated publics’ concerns over access to health care.

ECONOMICS

Participants were apprehensive about the economic impacts of a pandemic on at-risk populations. Both Boston and Kansas City were worried about leave and job protection issues that would affect financial resources. They worried about the “lack of a safety net” and “support resources for those financially impacted due to government mandated closings.” Stakeholders also expressed concern over the effects of absenteeism.

TRANSPORTATION

Participants in both Boston and Kansas City felt that the current transportation system in their area did not serve at-risk populations adequately. In Boston, participants at one table said they often saw public transportation workers slam doors in front of a blind person. In Kansas City, many participants expressed fear that a system breakdown during a pandemic would further hinder access to health care.

FOOD AND SUPPLIES

Participants in both Boston and Kansas City questioned how they would gain access to basic needs such as (food, water, paper supplies, diapers) during a pandemic.

UTILITIES

In Kansas City, a few tables expressed concern over access to utilities (gas, water, electric) particularly with respect to health care (such as those who need machines for medical reasons). In Boston, this topic was minimally discussed.

POPULATION MOVEMENT

At the NSM, participants were particularly concerned over the influx of people from more populated areas to more isolated rural areas. They strongly agreed (86%) that due to this expected influx, people in tribal and other rural and isolated areas need to be included in influenza pandemic planning. During discussions, the reason given for this concern was that people may leave urban areas and retreat to more isolated and rural areas.

IMPLEMENTATION

Stakeholders were also concerned about implementation of the guidance. A small majority of respondents (53%) agreed that the guidance should discuss implementation with a timeline for action. This reflects their concern that “plans such as this start with great intentions but implementation may cause it to take on another form.” Stakeholders also expressed concern over bureaucratic barriers that would make implementation difficult. They strongly agreed (71%) that credentialing and other bureaucratic barriers to this strategy should be addressed.

E. Polling Results on Solutions

Participants in all three meetings offered a variety of suggestions to meet the concerns and needs of at-risk populations during a pandemic. Suggested solutions converged around a number of common themes.

Table 12: Responses to communication solutions for at-risk populations during a pandemic

	Agree	Disagree
Public health messages should be phrased positively (i.e. most people will not get sick) to avoid creating panic and negative results. (<i>Boston</i>)	30%	56%
The media should have pre-recorded messages in American Sign Language (ASL) and other languages to provide information during a pandemic. (<i>Boston</i>)	96%	0%
Neighborhood organizations would be an effective way to share information. (<i>Kansas City</i>)	87%	0%
Communities, community-based organizations (CBO), and faith-based organizations (FBO) should be utilized and empowered to provide public health emergency and awareness information. (<i>NSM</i>)	93%	0%
The Advisory Panel should develop a short 4-page leaflet with a list of resources and recommendations for state and local governments. (<i>NSM</i>)	63%	13%

Communication was both a large topic of concern and an area where many solutions were presented. These solutions involved the content, source, and media outlet of the message. In

Boston, respondents disagreed (56%) that the content of public health messages should be phrased positively (i.e. most people will not get sick) to avoid creating panic and negative consequences such as stockpiling medication. In discussions, Boston participants also suggested that messages should be composed of simple language, pictures, and international symbols, and that all technical terms should be defined. Kansas City participants emphasized that information should be available in a variety of languages and dialects. Stakeholders suggested that the messages should contain information about care of self and others.

Participants in all meetings also made many suggestions about the source of the message. Boston participants strongly agreed (96%) that the media should have pre-recorded messages in ASL and other languages to provide information during a pandemic. Other sources of information identified by Boston participants were health care institutions, schools, senior centers, community centers, the library, phone chains, and mailings. Kansas City participants strongly agreed (87%) that neighborhood organizations would be an effective way to share information, and suggested creating an information hotline. Stakeholders strongly agreed (93%) with using communities, CBOs, and FBOs to provide public health emergency and awareness information, and using more non-traditional media such as teleconferences. In terms of media, Boston participants suggested using flyers to reach out to the homeless and translators in hospitals and doctors' offices. Finally, the stakeholders agreed (63%) that the Advisory Panel should develop a short four-page leaflet with a list of resources and recommendations for state and local governments.

Table 13: Responses to community preparedness solutions for at-risk populations during a pandemic

	Agree	Disagree
The city should conduct transportation drills (i.e. evacuation, food delivery) that include people with disabilities. (<i>Boston</i>)	82%	9%
You would support a voluntary registry so that at-risk people can sign up to get critical information and be identified so that responders can assist them quickly. (<i>Boston</i>)	81%	7%
I would be better prepared for a pandemic if my faith-based community was more involved in preparedness activities. (<i>Kansas City</i>)	77%	9%
A community-wide pandemic influenza exercise should be held that includes at-risk populations so that at-risk populations can learn from participating in the drills. (<i>Kansas City</i>)	94%	0%
You would participate in developing neighborhood level plan to mark locations for emergency services. (<i>Kansas City</i>)	83%	2%
Planning needs to focus on the role of local communities and individuals in preparing and responding to an influenza pandemic. (<i>NSM</i>)	93%	7%

Community preparedness was another topic where there were many suggested solutions across all three meetings. Primarily, these suggestions involved community preparedness drills. In Boston, 82% agreed that the city should conduct transportation drills (i.e. evacuation, food delivery) that include people with disabilities. Participants in Kansas City agreed with this suggestion – 94% of participants agreed that a community-wide pandemic influenza exercise

should be held that includes at-risk populations so at-risk populations can learn from participating in the drills. Participants also discussed that neighborhood plans should be created and locations for support identified in advance with public symbols used to identify these locations. They strongly agreed (83%) that they would participate in developing a neighborhood plan to mark locations for emergency services.

Stakeholders also strongly agreed (93%) that planning needs to focus on the role of local communities and individuals in preparing and responding to an influenza pandemic. They reasoned that people would receive services and education more readily from local CBOs and FBOs rather than government entities. Stakeholders emphasized that establishing or drawing on existing networks would be an important component of preparedness. As an example, one network mentioned was the Florida Special Needs Shelter and Registry Program. This program links companies and organizations that have a responsibility for service delivery to at-risk populations. In Boston, a voluntary registry was thought to play an important role in preparedness, with 81% agreeing that a voluntary registry would enable at-risk people to receive critical information and be identified so that responders can assist them quickly.

Participants in Kansas City did not mention a registry but wanted the faith-based community and local governments to play a key role. When polled, 77% agreed that they would be better prepared for a pandemic if their faith-based community were more involved in preparedness activities. Kansas City participants also discussed that local government should have the power and resources to take action quickly.

Table 14: Responses to health care solutions for at-risk populations during a pandemic

	Agree	Disagree
Everyone should be able to receive healthcare services during a pandemic even if they do not have health insurance. <i>(Boston)</i>	98%	0%
During a pandemic people should be allowed to stockpile prescription medication that is normally only distributed in 30-day supplies. <i>(Boston)</i>	44%	33%
Access to health care during a pandemic should be provided regardless of income or ability to pay. <i>(Kansas City)</i>	96%	2%
Mobile health clinics would improve access to care during a pandemic influenza outbreak. <i>(Kansas City)</i>	87%	0%
Facilities should be available for sick homeless people during a pandemic. <i>(Kansas City)</i>	96%	2%
Local community members should become involved in community preparedness by receiving training in basic medical skills. <i>(NSM)</i>	50%	21%

Participants generated many suggestions on health care issues. Respondents in Boston and Kansas City strongly agreed (98% Boston, 96% Kansas City,) that all should be able to receive health care services during a pandemic regardless of ability to pay. Those in Kansas City also agreed (87%) that mobile health clinics would ensure at-risk populations' access to medical care. They strongly agreed (96%) that specialized facilities for the homeless population should be created. The high level of support for these facilities may have resulted from the fact that a large number of public participants were either part of, or a representative of, the homeless community.

During discussion, Kansas City participants suggested training others to support the emergency response. This sentiment was shared by the stakeholders. When polled on whether local community members should receive training in basic medical skills as a way to become involved in community preparedness, 50% agreed. While this number does not show strong agreement, 29% of participants were neutral, indicating a lack of strong disagreement.

A final common theme in the topic of health care solutions was access to medicine during a pandemic. In Kansas City, participants suggested having free medicine or quantitatively increasing the insured access to their regular medications. Participants in Boston discussed this solution also, but when polled on the issue, did not show strong support. Only 44% agreed that during a pandemic people should be allowed to stockpile prescription medication that is normally only distributed in 30-day supplies. The lack of strong agreement on this solution reflects disagreement voiced by some participants on the notion of allowing medication to be stockpiled for fear of misuse.

Table 15: Responses to personal preparedness solutions for at-risk populations during a pandemic

	Agree	Disagree
Communities should provide opportunities for one-on-one personal preparedness planning for individuals who are at-risk? (<i>Boston</i>)	67%	21%
Individuals, including those at-risk, should be encouraged to prepare first, and then ask for help? (<i>Kansas City</i>)	64%	15%

Personal preparedness was another common solution that gained much support from engagement participants. In Boston, the theme of individual preparedness was emphasized. When polled, 67% agreed that communities should provide opportunities for one-on-one personal preparedness planning for individuals who are considered at-risk. Kansas City participants also agreed (64%) that individuals should be encouraged to prepare first then ask for help. Although not specifically polled on this issue, stakeholders also discussed how personal preparedness would be a key factor in protecting the at-risk community during a pandemic. Although there was much public support on the solution of personal preparedness, participants also stressed that outreach, education, and support through a buddy system were necessary.

Table 16: Responses to economic solutions for at-risk populations during a pandemic

	Agree	Disagree
Having rules in place to prevent you from losing your job during a pandemic would help you and your family make it through a pandemic. (<i>Boston</i>)	81%	11%
Government should apply pressure and provide assistance to businesses so sick employees can stay home without losing their jobs. (<i>Kansas City</i>)	79%	9%

Establishing government rules to safeguard jobs was a common solution suggested by participants at both the Kansas City and Boston meetings. In Boston, 81% of participants agreed that having rules in place to prevent them from losing their job during a pandemic would help them and their family make it through an event. Participants in Kansas City demonstrated similar support for such an idea – 79% agreed that the government should apply pressure and provide assistance to businesses so sick employees can stay home without losing their jobs. Although not

polled on these suggestions, Kansas City participants also discussed giving companies that allow sick employees to stay home tax breaks and suspending payment of major bills if a person gets sick and has to stay home.

FOOD AND SUPPLIES

In Boston, the issue of securing basic food and supplies appeared to be more of a topic of concern than at any other meeting. There was strong agreement (72%) in this city and no disagreement that the National Guard should be called in to help at-risk populations get food and other supplies. No solutions to the concern over food and supplies were proposed at any other meeting.

F. Focus Group Results

Following the Boston meeting and NSM, a few participants stayed to contribute to a focus group discussion on the overall process. Focus group participants were asked a series of questions pertaining to the reason for their attendance; what they believed worked best or least during the meeting; how their knowledge of pandemic influenza changed; and what principles they believed were important in making decisions about at-risk populations in pandemic planning.

Boston participants gave a wide variety of reasons for attending. Some were members of at-risk populations and wanted to learn more about what to do in the case of a pandemic and how services might be impacted. Others were caretakers of disabled people and wanted to learn what they need to do in a case of a pandemic. Finally, there were representatives from organizations who wanted to learn about how at-risk populations can be reached and engaged.

Overall, participants both in Boston and at the NSM agreed that the best part of the day was the information they received and the chance to learn from and dialogue with others. Boston participants appreciated being consulted about at-risk pandemic planning. Both groups felt that they gained more knowledge as a result of the day. When asked what could be improved, participants in Boston suggested simplifying the agenda because some participants may have suffered from “information overload and exhaustion.” As a result of this suggestion, the agenda was streamlined for subsequent meetings. NSM focus group participants suggested that bringing more visibility to the event would have increased its impact.

Boston participants felt confident “that the input we provided today will be used by policy makers to inform the development of the guidance.” Stakeholder participants also believed that due to the culture change that occurred after Katrina, decision-makers would use the information received and “run with it.” Finally, focus group participants at both meetings stressed that inclusion, preparation, and coordination should be guiding ideals when dealing with the at-risk population.

G. Debriefing Results

Following each of the three meetings, facilitators and note-takers met to reflect on the process and offer suggestions for improvement. Many of these suggestions were adopted in an effort to improve subsequent meetings. Overall, facilitators and note-takers commented that it was a positive experience. They believed that the “honesty, openness, and integrity brought to these people” was extraordinary. Specifically, they commented on the diversity of participants, the agenda, the discussion materials, the polling process, the impact on participants, and site locations.

They stated that participants were diverse and represented numerous health issues of at-risk populations. Facilitators and note-takers commented that the agenda was flexible and finished ahead of schedule. A facilitator in Boston suggested moving the presentations until later in the schedule and beginning with dialogue because “participants were not happy with the services they were getting, so having government give presentation right off the bat may not be seen as positive.” Stakeholders commented that the input from Boston and Kansas City representatives was very helpful.

Facilitator and note-taker feedback on material from the Boston meeting led to a revision of all material before subsequent meetings. Boston facilitators commented that the “reading level on all materials for the meeting needs to be reviewed and lowered,” that directions should be in “plain English” and that “questions were worded above the target audience.” They suggested using more “everyday language or giving examples.” After changes based on this feedback, comments were more positive. For example, stakeholder facilitators commented that “the materials for leading the discussion were good.” However, Kansas City facilitators and note-takers continued to question the wording and the structure of discussion questions. They commented that “starting off with the definition was difficult and that instead “who do you know is most vulnerable?” would have been a good place to start.

Despite these issues with the wording of discussion materials, facilitators and note-takers overall believed that “the quality of ideas was good and the participants were truly engaged.” They thought that letting the pollables emerge really validated participants’ perspectives. At the same time, facilitators and note-takers suggested explaining the polling process more thoroughly to participants. They also cited that electronic rather than handwritten polls would have been better.⁸ The biggest concern expressed regarding the pollable questions was that they were changed too much from how they were originally stated. One facilitator cautioned that when “you ask for public input, please be wary of editing public comment.” Overall facilitators and note-takers suggested bringing the polled questions back to the groups and having them approve or proof the questions before polling.

When assessing the impact on participants, facilitators and note-takers overwhelmingly commented that participants felt heard and validated. They were enthusiastic, had energy, and a curiosity to learn more on the topic. At the same time, facilitators commented that participants were a bit unclear about the purpose of the meetings. They were “unclear as to if they were here to give information or to get information.” While those in Boston commented that people felt as if they came away with information “about public health resources for follow up information and support,” facilitators in both cities commented that participants wanted to take away more from the meeting. Those in Kansas City felt that participants wanted to come away with more information and resources, and Boston facilitators and note-takers suggested giving participants “goodie bags” filled with free items from the health department. This would be a way to “market and educate” participants. They also suggested putting hand sanitizer on the tables for everyone to use, which was adopted for subsequent meetings.

When commenting on site locations, facilitators and note-takers in Boston recommended that sites should be checked ahead of time for accessibility to bathrooms because some wheelchair-

⁸ Electronic polling methods were planned for all meetings, but after technical difficulties in Boston, paper balloting was introduced and subsequently used for Kansas City and the NSM.

reliant individuals had difficulty with the facilities. They also recommended having healthy food choices.

V. Summary

Overall, the ASTHO At-Risk Populations Project engagement meetings achieved their objectives. A fairly diverse group of participants came together to discuss the definition of at-risk populations, their potential needs during a pandemic, and solutions to fulfill some of these needs. Participants were truly engaged, discussion was rich, and participants offered a variety of strong recommendations for consideration. These recommendations influenced the wording and recommendations in the final guidance document.

The project also provided many lessons in regard to the public engagement process with at-risk populations. A diverse representation of at-risk populations requires adequate planning time so that sufficient outreach activities can be undertaken. Although participation was fairly diverse, more representation from other age groups, ethnicities, non-English speakers, parents of small children, and caretakers would have contributed to the richness of the insights provided. When engaging at-risk populations, the agenda should be flexible to meet the special needs of at-risk populations. As noted by facilitators, participants appreciated the flexibility of the agenda, but may have suffered from information overload. Locations should be carefully scrutinized to ensure that they meet the special needs of individuals with disabilities. Careful attention should be paid to the wording of all directions, presentations, and written materials to ensure thorough understanding. At-risk individuals can be informed and engaged and provide meaningful input that can be used to assist with public health decision-making. Participants were excited and carefully considered the issues presented to them. The quality of recommendations that emerged from the process was high and was useful for the guidance development process. Participants came away from the process empowered and wanting to do more in their communities to inform and prepare others. Federal, state, and local agencies should recognize the energy and enthusiasm that results from these processes and provide participants with the resources to become ambassadors in their community. These lessons will be useful as agencies and organizations work to engage at-risk populations further in public health decision-making.

VI. Appendices

Appendix A: Polling Results

Boston Polling Tally Sheet

Participants were asked to please check off the box, which most accurately reflects their response to the question, and to consider the pandemic questions in light of a moderate to severe pandemic based on the factual scenario they had in their materials. The numbers below equate to the number of responses given in that category.

	<i>Strongly Agree (1)</i>	<i>Agree (2)</i>	<i>Neutral (3)</i>	<i>Do not Agree (4)</i>	<i>Disagree (5)</i>
1. Children should be named in the definition.	36	11	3	4	3
2. Mental health should be named specifically as an “at risk population.”	30	11	4	8	4
3. Having rules in place to prevent you from losing your job during a pandemic would help you and your family make it through a pandemic?	38	8	5	3	3
4. Social isolation puts you at greater risk than geographic or cultural isolation?	26	13	8	8	2
5. The media should have pre-recorded messages in ASL and other languages to provide information during a pandemic?	49	6	2	0	0
6. Would you support a voluntary registry so that at-risk people can sign up to get critical information and be identified so that responders can assist them quickly?	40	6	7	3	1
7. Existing networks of communication work well enough for relaying information to at-risk populations during a pandemic.	0	1	7	27	22
8. The National Guard should be called in to help at-risk populations get food and other supplies.	25	16	16	0	0
9. People with more than one at-risk factor (i.e. economically disadvantaged and blind) should be specifically mentioned in the definition?	9	10	18	16	5

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10. People who participate in risky behavior (i.e. gang activity or substance abuse) should be included in the definition.	4	2	18	17	16
11. Communities should provide opportunities for one on one personal preparedness planning for individuals who are at-risk.	30	8	7	9	3
12. During a pandemic people should be allowed to stockpile prescription medication that is normally only distributed in 30-day supplies.	14	11	13	15	4
13. The city should conduct transportation drills (i.e. evacuation, food delivery) that include people with disabilities.	41	6	5	4	1
14. Public health messages should be phrased positively (i.e. most people will not get sick) to avoid creating panic and negative results.	9	8	8	20	12
15. Everyone should be able to receive healthcare services during a pandemic even if they do not have health insurance?	54	2	1	0	0

Kansas City Polling Tally Sheet

Participants were asked to please check off the box, which most accurately reflects their response to the question, and to consider the pandemic questions in light of a moderate to severe pandemic based on the factual scenario they had in their materials. The numbers below equate to the number of responses given in that category.

	<i>Strongly Agree (1)</i>	<i>Agree (2)</i>	<i>Neutral (3)</i>	<i>Do not Agree (4)</i>	<i>Disagree (5)</i>
1. Do you support the working group definition (6 factors) as written?	9	15	10	11	2
2. Do you agree or disagree that these factors include the most vulnerable people you know?	8	24	6	6	3
3. A community-wide pandemic influenza exercise should be held that includes at-risk populations so that at-risk populations can learn from participating in the drills.	24	20	3	0	0

4. I am likely to get information about an emergency from television.	16	20	10	0	1
5. Discrimination whether intentional or not interferes with delivery of important health services.	23	15	5	1	3
6. I have been adversely affected by needing to go to more than one place to get healthcare services.	21	13	10	1	2
7. Workers who maintain public infrastructure and those who directly aid at-risk persons should be treated first.	24	14	5	2	2
8. There should be an alternative to getting medicine from a doctor.	20	17	7	1	2
9. Mobile health clinics would help me get access care during a pandemic influenza outbreak.	29	12	6	0	0
10. Access to health care during a pandemic should be provided regardless of income or ability to pay.	37	8	1	0	1
11. Neighborhood organizations would be an effective way to share information.	31	10	6	0	0
12. I know where I can go to get help and information during a pandemic.	10	9	9	14	5
13. People should not be required to show identification in order to get treatment in a pandemic.	19	10	9	5	4
14. I would be better prepared for a pandemic if my faith-based community was more involved in preparedness activities.	21	15	7	3	1
15. Facilities should be available for sick homeless people during a pandemic.	34	11	1	1	0
16. I would participate in developing neighborhood level plan to mark locations for emergency services.	29	10	7	1	0
17. Individuals including those at-risk should be encouraged to prepare first, and then ask for help.	17	13	10	5	2
18. Government should apply pressure and provide assistance to businesses so sick employees can stay home without losing their jobs.	33	4	6	3	1

NSM Tally Sheet

Participants were asked to please check off the box, which most accurately reflects their response to the question, and to consider the pandemic questions in light of a moderate to severe pandemic based on the factual scenario they had in their materials. The numbers below equate to the number of responses given in that category.

	<i>Strongly Agree</i> (1)	<i>Agree</i> (2)	<i>Neutral</i> (3)	<i>Do not Agree</i> (4)	<i>Disagree</i> (5)
A. Do you support the working group definition (6 factors) as written?	2	4	3	4	2
B. These factors include the most vulnerable populations you know.	5	5	0	3	0
1. Undocumented persons should be included in the planning for pandemic influenza response.	7	6	0	0	1
2. The HHS definition should be adopted in this guidance and the ARPP should be presented to provide further detail.	5	6	2	0	1
3. Due to expected influx, people in tribal and other rural and isolated areas need to be included in influenza pandemic planning.	6	6	0	1	1
4. Planning needs to focus on the role of local communities and individuals in preparing and responding to an influenza pandemic.	12	2	0	1	0
5. Because of the scope of this document, discrimination should be defined as an overarching attribute instead of within bullet points.	4	5	2	2	2
6. The guidance should discuss implementation with a timeline for action.	1	7	2	3	2
7. Children should be added to the examples of “unaccompanied people.”	2	6	2	1	3
8. The Advisory Panel should develop a short 4-page leaflet with a list of resources and recommendations for state and local governments.	5	5	4	1	1

9. We should enable local community members to become involved community preparedness by receiving training in basic medical skills.	5	2	4	3	0
10. We should address credentialing and other bureaucratic barriers to this strategy.	3	7	1	2	1
11. Communities, CBOs and FBOs should be utilized and empowered to provide public health emergency and awareness information.	9	5	1	0	0

Appendix B: Participating Organizations

ASTHO would also like to thank the following additional participating organizations for their hard work and dedication to this project and to at-risk populations. Their participation was critical to the success of this initiative.

- Massachusetts Department of Public Health
- City of Boston Public Health Commission
- Brookline, Massachusetts Health Department,
- Cambridge, Massachusetts Public Health Department
- Boston University School of Public Health
- One KC Voice/Consensus
- State of Missouri Department of Health and Senior Services
- State of Kansas Department of Health and Environment
- Kansas City Health Department
- Johnson County Health Department

Appendix C: Meeting Agendas

Public Engagement Meeting, Boston University School of Medicine, Boston, MA, March 8, 2008

8:00	Training for Facilitator and Note-takers Registration/Continental Breakfast (9-10am)	
10:00	Welcome and Opening Remarks	ASTHO/State and Local Officials
10:10	Overview of the Day	Keystone
10:15	Background: Pandemic Flu 101	Donna Lazoric, MA Dept. of Health
10:30	Q and A	Keystone
10:40	Presentation #2: At-Risk Populations During a Pandemic	Paul Jarris, ASTHO
10:55	Q and A	Keystone
11:15	Breakout Groups	Keystone
12:15	LUNCH	Table Facilitators
1:00	Breakout Group Reports	Facilitators
1:45	Large Group Discussion	Keystone
2:00	BREAK	
2:15	Polling	Keystone
3:00	Discussion	Keystone
3:15-3:20	Wrap up & Adjourn	Anna DeBlois, ASTHO
3:20- 3:30	Stipend distribution	Keystone
3:30-3:45	Focus Group/Evaluation	Keystone
3:30-3:45	Facilitator/Note-taker Debriefing	Keystone

Public Engagement Meeting, South-Broadland Presbyterian Church, Kansas City, MO, March 15, 2008

8:00	Registration/Continental Breakfast	
9:00	Welcome and Opening Remarks	ASTHO/State and Local Officials
9:45	Background: Pandemic Flu 101	Benjamin Schwartz, HHS
10:30	BREAK	
10:45	Presentation #2: At-Risk Populations During a Pandemic	Leon Vinci, Johnson Co. Dept. of Health
	Q And A	
11:30	Guidance for the Participants	ASTHO
11:45	Breakout Groups	Table Facilitators
	LUNCH	
	Resume Breakout Group Discussion	
1:30	Breakout Group Report-Out – Major themes	Table Facilitators/Keystone
2:00	Large Group Discussion [Questions on influenza or other topics at this time]	Keystone
2:15	Survey Polling and Discussion	Keystone
2:45	Wrap Up /Next Steps / Thank You	ASTHO / CDC
3:00	Adjourn / Stipend Distribution	Keystone
3:00-3:45	Evaluation Focus Group	Keystone

National Stakeholders' Meeting, Washington Hilton, Washington, D.C., March 20, 2008

7:30	Registration/Continental Breakfast	
8:30	Welcome and Opening Remarks, Overview of the day	ASTHO/CDC/Keystone
9:00	Background: Influenza Overview Q and A on topic	Toby Merlin, CDC
10:00	BREAK	
10:15	Presentation #2: Responding To The Challenge Q & A on topic	John Auerbach, Chair, ARPP Advisory Panel
11:00	Summary presentation and Panel Discussion with participants from Boston and Kansas City Meetings	Keystone
11:30	Directions to the Participants	ASTHO
11:45	Breakout Groups	Table Facilitators
12:30	WORKING LUNCH	
1:30	Breakout Group Report-Out – Major themes	Table Facilitators/Keystone
2:00	Large Group Discussion, Questions on influenza or other related topics	Keystone
2:30	Polling and Discussion	Keystone
3:15	Wrap Up and Next Steps	ASTHO
3:30	Adjourn	Keystone
3:45	Evaluation Focus Group	Keystone

Appendix D: Comment Cards

Comments are as written by participants and transcribed verbatim.

Boston Comment Cards

1. Where does this form of the flu come from?
2. Do the health emergency departments have any emergency preparation?
3. Shouldn't there be special funding available so that people who cannot pay for the vaccine can still be immunized?
4. Why can't people walk into any type of clinical or hospital setting to obtain the vaccination without being a member?
5. Pandemic Emergency. How would they handle child molesters?
6. Shortage of bees. Do you know if they have the flu? How do I get someone to speak in my community?
7. As far as getting the information out, several people mentioned go to our website, which is fine except that what do you do for people without computers or knowledge on how to use them?
8. Can a person get a transcript of this meeting? Also, can we get the information that is in the packets emailed to us.
9. How was the notice for this meeting distributed? Who chose that list of invitees?
10. You should consider setting up some form of internet based participation for people who could not attend (i.e. chat, video, podcast, etc.)
11. I want to get this important information to share with my Spanish partner providers. Can I have this information in Spanish? Can someone come with me to make a meeting to the Spanish care providers and the delivery this is important information to them?
12. I feel the polling process is far less valuable because of ambiguous wording/ lack of context. i.e. deploy National Guard as opposed to what other options? One- on-one education relative to how much available/ what other resources needed. Rules in place, what are they saying if they are valuable.
13. To the CDC: We've been participating in discussions about needs of at-risk populations for two years. The list of concerns have been created many time in many forums. When will we be invited to a discussion of proposed solutions?
14. Consider timing the agenda so that the input of questions the electronic polling happens while the group is having lunch as a more effective use of time or plan a presentation/ speaker for the input time. I felt like a hurry up and wait.
15. More than 2 years ago, I authorized our agency's COOP and submitted it to EOHHS. Beyond receiving acknowledgement of receipt of the plan, I never received any feedback on the plan. Not being an expert in this field, I do not know if there are holes in the plan or how my agency will interact with others in the community. How can this be tightened or tested?

Kansas City Comment Cards

1. Who is at-risk? The immigrants are at higher risk. For the fact that their status is not legal in the U.S.A.
2. Why don't they put a pamphlet in childcare for the parents?
3. Why can't my family get vaccinated regardless of what group I fit in?
4. Key message: What happens after this? How is this going to be used? Part of and contributing to national framework. You own this information. Key for our development of guidance.
5. Don't forget to give info to the churches so they can distribute.
6. Rural location- injury- Where get medical help? Ask to stay home.
7. What can we do to help the aging more to help them to be care for at home?
8. How can we put more caring people into the key roles to help the aging and stop taking advantage of the aging?
9. I have to have surgery on my knee in 3 to 4 months. My doctor has had me to get dental and rotator cuff repaired, He said we need to do everything possible to ward off infection. Will this delay an operation date? Or increase the odds of infection?
10. How do we reach people? Churches, Schools, Pharm., Word of mouth, Radio or TV, Newspaper, Meals on Wheels.

Appendix E: Glossary of Terminology/Acronyms

ASTHO: Association of State and Territorial Health Officials

CBO: Community-based organization

CDC: Centers for Disease Control and Prevention

CIDRAP: Center for Infectious Disease Research and Policy

FBO: Faith-based organization

HHS: Department of Health and Human Services

HIPAA: Health Insurance Portability and Accountability Act

NACCHO: National Association of County and City Health Officials

NSM: National Stakeholders' Meeting