The New York State Department of Health and The Keystone Center

Community Meetings on Pandemic Influenza Final Report
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I. Executive Summary

Pandemic Influenza planning is a priority public health issue for the State of New York. Over the past few years, concern over the possible emergence of an influenza virus that could lead to a pandemic has created the need for increased public health preparedness, pandemic education, and planning. The New York State Department of Health (NYSDOH) and local public health organizations desire to raise public awareness of current pandemic planning assumptions and strategies within targeted audiences. The State and community organizations wish to educate the public, as well as ascertain to what extent individuals’ knowledge, attitudes and beliefs are aligned with current State core planning assumptions. This will allow the State and local organizations to be better prepared, as well as prepare the citizens of New York for an influenza pandemic. Having this information will provide a reality check for the planning process and identify gaps, barriers, and unintended consequences that would impede a successful response during a public health emergency. State and local public health officials hope to create an ongoing dialogue about complex issues and bring together diverse parties to consider solutions to inform New York’s pandemic influenza planning.

The NYSDOH collaborated with The Keystone Center and other key partners in public health preparedness, including local health departments (Cortland County, Chautauqua County, and Nassau County) and the University at Albany Center for Public Health Preparedness to host daylong, public engagement meetings at four sites on April 12, 2008. Planners attempted to recruit 25-30 participants for meetings in Cortland County, Chautauqua County, and Nassau County and 45-50 participants for one meeting in the Albany area. The goal was to have representation from at-risk/vulnerable populations such as the elderly, individuals with disabilities or mental health issues, tribal nations, minority New Yorkers and vulnerable children. The objective was to have both service providers and consumers at these meetings.

Each meeting followed a similar structure to keep interactions and information being gathered consistent (see agenda, Appendix A). Following greetings by the local health organization, the NYSDOH, and The Keystone Center, participants watched a video providing background information necessary to have an informed discussion on pandemic influenza. After a question and answer session, participants met in facilitated small group discussions and addressed a series of questions meant to discover specific needs of at-risk populations during a pandemic.
General themes that emerged during discussions were issues of trust, self-reliance, taking action in the community, and stockpiling essential items, particularly the difficulty of having sufficient prescription medications on hand, which was noted at three of the meeting locations.

Changes in Rx Regulations are Needed

Through polling and discussion, participants identified the following specific areas of need for at-risk populations during a pandemic.

1. **Stockpiling:** Participants are confident in their ability to stockpile food, essential supplies and medicine if they are given information about how to do this and what items are needed. Regulations need to be adapted to support/allow storage of prescription medications. In addition, plans must be made to help those in the community for whom stockpiling might be difficult.

2. **Access to Quality Information:** Information about all aspects of pandemic planning should come from health care providers, help-lines, and community and governmental leaders.

3. **Medication:** Participants’ willingness to take and give medication that might help them but has not been proven safe would hinge on whether the benefits outweigh the risks, especially concerning children.

4. **Governmental Support:** Every level of government must build capacity and demonstrate that all people are being treated fairly in terms of pandemic planning and preparedness.

5. **Community Support:** Communities should begin active planning by drawing on interested individuals and networks to provide necessary education, support, and resources, especially relating to childcare and provision of essential supplies.
6. Health Care System: The health care system must address issues of aging workers and the policy for staff retention during a pandemic.

7. Economics: Economics as a motivating factor for compliance to public health guidance must be examined.

8. Personal Preparedness: Individuals must be motivated to become prepared.

9. Social Distancing: Individuals must be informed about what they would be asked to do in the event of a severe Individuals for whom complying with social distancing might pose a hardship need to be identified in advance and alternatives devised.

Following polling, some participants met for a focus group to assess their meeting. The most frequent suggestion from focus group participants was that citizens wanted to come away from the meeting empowered to become active in their communities. Facilitators and note-takers also emphasized that participants wanted something to take away from the meeting such as a specific charge, resources, or information.

These important insights will be useful for the NYSDOH as the department continues its pandemic planning.

II. Background

Pandemic Influenza planning is a priority public health issue for the State of New York. Over the past few years, concern over the possible emergence of an influenza virus that could lead to a pandemic has created the need for increased public health preparedness, pandemic education, and planning. The New York State Department of Health (NYSDOH) and local public health organizations desire to raise public awareness of current pandemic planning assumptions and strategies within targeted audiences. The State and community organizations wish to educate the public, as well as ascertain to what extent individuals’ knowledge, attitudes and beliefs are aligned with current State core planning assumptions. This will allow the State and local organizations to be better prepared, as well as prepare the citizens of New York for an influenza pandemic. Having this information will provide a reality check for the planning process and identify gaps, barriers, and unintended consequences that would impede a successful response during a public health emergency. State and local public health officials hope to create an ongoing dialogue about complex issues and bring together diverse parties to consider solutions to inform New York’s pandemic influenza planning.

The NYSDOH collaborated with The Keystone Center and other key partners in public health preparedness, including local health departments and the University at Albany Center for Public Health Preparedness, to host a series of daylong, four-site public engagement sessions.
The purpose of the meetings was to ask members of the public to provide input about pandemic planning and things people will be asked to do to help themselves, their families, and each other.

III. The Community Engagement Process
Four meetings were held at various locations across the state on April 12, 2008. The meetings addressed critical health emergency issues, including those related to prioritization of medical resources during a pandemic.

The specific goals of the meetings were:
1. To obtain input from the public on the state’s pandemic planning efforts;
2. To create a meeting environment that will enhance the opportunity of community members to discuss a critical health issue with public health officials; and
3. To conduct the meetings in a trust-building manner.

The NYSDOH led recruitment efforts. The goal was to have 25-30 participants at each of the meetings in Cortland County, Chautauqua County, and Nassau County and 45-50 participants at one meeting in the Albany area. Planners recruited representatives of at-risk populations such as the elderly, individuals with disabilities or mental health issues, tribal nations, minority New Yorkers and vulnerable children, among others. The recruitment objective was to have representation from both service providers and consumers.

Citizen input received from these meetings will inform state officials who currently are refining preparedness and response strategies in preparation for an influenza pandemic. This input will be considered along with other information, as pandemic plans are updated and revised.

IV. Methods
Each meeting followed a similar structure to keep interactions consistent (see agenda, Appendix A). Following greetings by the local health organization, the NYSDOH, and the Keystone Center, participants watched a video providing background information necessary to have an informed discussion on pandemic influenza. At each meeting site, a local health expert then addressed questions from participants. General trends in questions from the meetings included: stockpiling medicine and food, communication of information during a pandemic, vaccination distribution, and differences between seasonal influenza and pandemic influenza. Questions and answers from all meetings are detailed in Appendix B.

Participants then met together in facilitated small groups to work through a series of six main questions and smaller discussion points. Any points raised that were not on topic were written on note cards to be addressed later in the day. These comments are transcribed and are included in Appendix C. The facilitated questions participants addressed were:
1. During a pandemic, if you or someone in your family got sick, could you follow instructions to stay away from hospitals or doctors’ offices unless your symptoms were truly life threatening?

2. During a pandemic, if you are directed to stay away from crowded places, including day care, elder care, worship services, meal sites or other support services, how likely are you to do it?

3. During a pandemic, given that there may not be enough lifesaving medication to go around, does it make sense to you that certain groups of people will be treated before other groups of people, and supplies might run out before you can get the medicine you need?

4. During a pandemic, would you accept a medication for you or your children that the medical profession strongly believes would help you and or/be lifesaving, but is not fully proven to be both safe and effective?

5. If you were told to do something that will pose an extreme hardship, how likely would you be to trust that the information is true?

6. Before an emergency like a pandemic, will you stockpile at least a two-week supply of emergency food and supplies, including canned food, bottled water and any medicines you take regularly?

During discussions, small group participants also proposed pollable questions meant to target needs and solutions of at-risk populations during a pandemic. Once pollable questions were formulated, participants rejoined the larger group to participate in a paper ballot polling exercise. Participants in all meetings were polled on fourteen (14) baseline questions and indicated their level of agreement according to a five point Likert scale. Participants then addressed the pollable questions proposed by the small groups (complete polling results are located in Appendix D). All meetings adjourned with a general question period and discussion of next steps. After the meeting, interested participants met in small focus groups to reflect on the day and make suggestions. Facilitators and note-takers were given an evaluation form to complete. Complete notes from the focus group sessions are listed in Appendix E and the summary of information from the Facilitator/note-takers are located in Appendix F.
V. Results

A. Participant Demographics

Overall, participants were diverse in terms of age, ethnicity, socio-economic backgrounds, experience with the issue of pandemic influenza, and special needs. Participation in the Albany-area meeting was especially diverse with representation ranging from individuals with physical and cognitive disabilities, service providers, African Americans and Latinos. Participants in Cortland County were fairly diverse in terms of age, socio-economic backgrounds and special needs. In Chautauqua County, representation was not as diverse as expected with the majority of participants being health care workers. However, representatives serving the Native American population were also present. Finally, participants in Nassau County represented an older, well-prepared population.

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1 Participant data are not necessarily representative of actual population demographics for the various jurisdictions
Participant numbers exceeded the goal of 25-30 participants in Cortland County and Nassau County. In Chautauqua County, a change in staff occurred two weeks prior to the event with a limited number registered. Despite the short time frame for recruitment, the new staff person excelled at bringing 19 people to the meeting. As expected, the Albany-area meeting had the largest number of participants falling slightly short of the goal of 45-50 participants.

Types of populations served were also noted by participants. Populations served included the poor, mentally ill, the aged, the elderly, nursing home residents, and the educationally at-risk. In addition, participants specified whether they had a physical or mental disability, or were living with a chronic disease.

Type of Disabilities across all Meeting Locations

2 Participant data are not necessarily representative of actual disability demographics across all meeting locations
B. Pre and Post Test Results

Participant knowledge increased on all questions as a result of the meeting. It increased significantly in the areas of vaccine, community control measures, and the roles of the population and the federal government.

<table>
<thead>
<tr>
<th>Breakdown of correct answers Pretest vs. Posttest</th>
<th>Pretest</th>
<th>Posttest</th>
</tr>
</thead>
<tbody>
<tr>
<td># people who took test:</td>
<td>116</td>
<td>112</td>
</tr>
<tr>
<td>%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Q1: What is influenza pandemic?</td>
<td>74</td>
<td>97</td>
</tr>
<tr>
<td>%</td>
<td>64%</td>
<td>87%</td>
</tr>
<tr>
<td>Q2: About how long would it take to produce a flu vaccine after the virus causing a pandemic is identified?</td>
<td>100</td>
<td>109</td>
</tr>
<tr>
<td>%</td>
<td>86%</td>
<td>97%</td>
</tr>
<tr>
<td>Q3: When will a pandemic flu vaccine be available?</td>
<td>74</td>
<td>107</td>
</tr>
<tr>
<td>%</td>
<td>64%</td>
<td>96%</td>
</tr>
<tr>
<td>Q4: Once vaccine has been made, to whom will it be made available?</td>
<td>57</td>
<td>99</td>
</tr>
<tr>
<td>%</td>
<td>49%</td>
<td>88%</td>
</tr>
<tr>
<td>Q5: How will a pandemic flu affect social gatherings?</td>
<td>75</td>
<td>105</td>
</tr>
<tr>
<td>%</td>
<td>65%</td>
<td>94%</td>
</tr>
<tr>
<td>Q6: In a severe pandemic, what might the general population be asked to do?</td>
<td>57</td>
<td>102</td>
</tr>
<tr>
<td>%</td>
<td>49%</td>
<td>91%</td>
</tr>
<tr>
<td>Q7: If a severe pandemic occurs, what involvement will the federal government have?</td>
<td>62</td>
<td>107</td>
</tr>
<tr>
<td>%</td>
<td>53%</td>
<td>96%</td>
</tr>
<tr>
<td>Q8: To be ready for a possible pandemic, what should you do to prepare?</td>
<td>91</td>
<td>109</td>
</tr>
<tr>
<td>%</td>
<td>78%</td>
<td>97%</td>
</tr>
<tr>
<td>Q9: What is the best way to prevent the spread of flu germs?</td>
<td>86</td>
<td>103</td>
</tr>
<tr>
<td>%</td>
<td>74%</td>
<td>92%</td>
</tr>
<tr>
<td>Q10: When will the next pandemic occur?</td>
<td>108</td>
<td>111</td>
</tr>
<tr>
<td>%</td>
<td>93%</td>
<td>99%</td>
</tr>
<tr>
<td>Total possible # correct answers</td>
<td>1160</td>
<td>1120</td>
</tr>
<tr>
<td>%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

- Pre-Test results were out of a total 116 participants. Post-Test results were out of a total 112 participants. Some questions were not answered by all participants.
C. Discussion Themes in Communities

As participants listened, talked, addressed discussion questions, and were polled, general themes emerged that characterize the discourse in each city. In the Albany area, the main theme was trust or lack of trust. People were particularly concerned about the specifics of stockpiling food and medicine. In Cortland County participants were very engaged. They really wanted information to take back to help educate their community. These sentiments were echoed in Chautauqua County as well. The main theme during that meeting was a desire to come away with something that would help their community be better educated and prepared. In Nassau County, the main theme was self-reliance. Participants also were concerned about determining how best to stockpile drugs and food due to a lack of trust toward politicians. These general themes are reflected in the polling results.

D. Similarities and Differences among Communities

Specific areas of need for at-risk populations during a pandemic emerged during discussions and polling. In the following section, quantitative and qualitative results are reported as they correspond to these findings. The specific need areas are: information, stockpiling, medication, governmental support, community support, the health care system, personal preparedness, economics, and social distancing. Similarities and differences among communities in terms of polling results and discussions are also identified. For sake of clarity in reporting the polling results, (1) strongly agree and (2) agree are grouped together, as are (4) disagree and (5) strongly disagree. Complete polling results are located in Appendix D.

Quality Public Health Information:

A significant need of at-risk populations voiced in polling and during discussions in all four meetings was access to reliable and easily understood public health information. Many participants felt that their ability to comply with other measures hinged on the availability, quality, and thoroughness of the information they receive. Continuity and clarity of information shared on a regular basis prior to any public health emergency was indicated to be one method to begin to build trust with community members.

Participants in all meetings were polled on the question “If you were told to do something that will pose an extreme hardship, which source would you rely on for trusted information: government official, health care provider, faith leader, community leader, media resource, health hotline and the internet.” According to the polling results, participants in all four meetings would be more likely to get information from a health care provider (highest percentage of any for all four meetings) and a health care hotline (ranked second in all meetings but Chautauqua County where government officials ranked second at 25%). This difference may be due to the high prevalence of health care workers in that city.
Participants in all four sites also would be least likely to get health information from a faith leader with this category receiving the lowest percentage at all meetings.

At the same time, the communities differed in their reliance on other information outlets. Cortland County and Albany-area participants would rely on the government and community leaders equally as trusted sources of information (these sources received an equal number of votes in both meetings and participants at both sites ranked them third on their list.) However, Nassau County participants placed community leaders much higher than government leaders, possibly due to the distrust of government officials that was expressed during that meeting. Participants stated that elected officials are just “too political.” In contrast, participants in Chautauqua County would more likely rely on government leaders than community leaders as information sources. In fact, government leaders received 25% of the vote in Chautauqua County where in all other communities the percentage was less than 11%.

Cortland County, Nassau County and Chautauqua County participants also listed the internet low on the list of relied upon sources; however, in the Albany area, it was preferred by 10.5% of participants. Interestingly, when later polled on the question “during a pandemic, I would look to my local health department website for the most reliable information,” 69% of the citizens in Chautauqua County agreed and 31% disagreed.

Many additional questions were posed in all four meetings regarding trusted sources of information. In Nassau County, 77% agreed that local and county health department information is perceived by local community members as more trustworthy and reliable than information from state and/or federal officials. In Chautauqua County, 94% agreed that the government (federal, state, local) is responsible to deliver the information, rather than the citizens seeking out the information themselves. A total of 86.7% also agreed that other organizations (e.g., churches, soup kitchens, grocery stores) should be involved in delivering the preparedness message and necessary information. Based on these results, it appears that generally participants want their health departments, government, and community leaders to take the lead on supplying information to citizens.

Additional questions posed by the meetings also addressed the type of information needed. This information included basic background community education, with 89.5% agreeing in the Albany area that this type of information is needed so citizens can prepare individually and at a neighborhood level. Specifically, this information might include ways to improve their immune system so their body is prepared to fight a pandemic flu virus, with 74% in agreement with this suggestion.
The information also should include details about stockpiling necessary items. Those in the Albany area felt poorly prepared with 68.4% of participants disagreeing that individuals know enough about what they need to stockpile in their homes to be prepared for a pandemic. They stressed that people need to be educated about the nutritional value of foods that they should stockpile in their home (81% agree). Those in Cortland County also strongly agreed (100%) that in a pandemic, if they knew what supplies were needed and where to get them, they would be willing to take care of a loved one at home.

Participants in Nassau County and Cortland County also wanted information on social distancing. In Nassau County many participants (77%) agreed that young people should be more educated on the importance of avoiding crowds (i.e., social distancing), in the event of a pandemic. This concern over young people among an older, well-prepared population is significant. In Cortland County 73.5% agreed that in a pandemic, if there were clear guidelines explaining at what point in the illness they or the person they are caring for should seek medical care, they would follow the guidelines. Agreement in both of these meetings reveals there is a need for more information about social distancing.

Finally, those in Chautauqua County wanted more information about medical countermeasures prioritization with 100% agreeing that persons in the community would better accept vaccine/medication prioritization if they received education about how it will improve the function and safety of the community as a whole. Such high levels of agreement with this suggestion reflects the sentiment expressed in this community that they wanted something to take away to help the larger community.

**Stockpiling**

Stockpiling or storage of basic necessities in preparation for a public health emergency was another need of at-risk populations identified by meeting participants.

In all four meetings, participants were first polled on the question, “In advance of an emergency like a pandemic, how likely will you be to stockpile at least a two-week supply of non-perishable food and emergency supplies, a two-week supply of bottled water, and a two-week supply of medicines you take regularly.” All four sites had strong agreement (over 80%) that they would be very likely to stockpile at least a two-week supply of non-perishable food and emergency supplies, stockpile at least a two-week supply of bottled water, and stockpile at least a two-week supply of the medicines taken regularly. Although there was considerable agreement, Chautauqua County participants were the most skeptical of being able to stockpile prescription medicine. This result was possibly because participants largely comprised health care workers who may have realized the difficulties of such an effort.
In short, it appears that participants in all meetings are willing to stockpile food and supplies for themselves but are not that confident that other individuals who live “paycheck to paycheck,” “the homeless,” “the disabled,” “the elderly,” or “don’t have the room” can. One group of participants at the Albany-area meeting cautioned that even if some of these individuals were given food, water and supplies, they might use them up before the pandemic. Other tables made suggestions of community food banks or mobile food canteens where food can be passed out.

Many additional questions were posed in all four meetings regarding stockpiling. In Chautauqua County, 69% disagreed that the current stockpile of food in their homes, agencies, and communities is sufficient for a pandemic. In contrast, however, 50% of participants in the Albany area agreed that their household has stockpiled enough food and water for a two-week period to be prepared.

Participants in the Albany area, Chautauqua County, and Nassau County also identified that there needs to be a change in the system for handling prescription drugs. In Chautauqua County, 67% disagreed that the current system allows for persons and agencies to stockpile medications in preparation for a pandemic. Participants in the Albany area and Nassau County suggested changes to the system by eliminating some regulatory barriers (Albany area 82%) and allowing individuals to have a two-week supply of daily prescription medication on hand (Nassau County 94%).

Based on the polling results of these additional questions, it appears that participants do not feel confident in knowing how and what food to stockpile nor in their ability to acquire prescription drugs. Although Cortland County participants did not specifically propose a question on stockpiling medication, the facilitators noted concern over participants’ ability to do this.

There was also a concern voiced about rotating of stored/stockpiled goods. Participants believed that some people may not realize that such supplies need to be rotated so nothing is stored longer than a useful shelf life. In some cases, that may be less than two years even if such articles are not opened because they do break down and become unusable.

**Medication**

The need for prioritization of medicines and vaccines for at-risk populations was another important topic of consideration by the communities.

Participants in all four meetings were first asked if they agreed that some people should be treated before others even if supplies might run out before **you** can get the medicine you need.
Participants in all meetings agreed with this statement; the Albany-area meeting having the lowest percentage of agreement at 78%, all others exceed 86% agreement.

When polled on whether they would accept a medication for yourself that the medical profession strongly believes would help you and or/be lifesaving, but is not fully proven to be safe and effective, most participants in Cortland County (82.3%) and Chautauqua County (94.8%) agreed. Strong agreement in Chautauqua County may be due to increased trust in the health care field since many participants were health care providers. In Nassau County (67.7%) and the Albany area (76%) there was still agreement, yet the level was not as high. In Nassau County and Chautauqua County, participants stated that the decision to take the medication would depend on how ill they were. In the Albany area, a lower percentage may reflect issues of trust with doctors and medicine in general.

When polled on whether they would be more likely to accept a medication for your children that the medical profession strongly believes would help you and or/be lifesaving, but is not fully proven to be both safe and effective, participants in Chautauqua County (87.5%) again strongly agreed, possibly due to increased trust in the health care field. Although more skeptical, a majority of participants in the other three meetings also agreed (Cortland County, 76.5%; Albany-area, 60.5%; Nassau County, 64.5%). Nassau County participants cautioned that people must use extreme caution before giving a medication to children.

A number of additional questions were offered by those in Albany-area and Nassau County meetings. In the Albany area, 68.4% agreed that the government should provide more incentives to all pharmaceutical companies to produce/develop vaccine and antivirals. Nassau County participants saw the need for providing at-risk individuals with antivirals. A total of 87.1% agreed that in the event of pandemic influenza, antivirals should be targeted to the high-risk groups most affected by a pandemic. Participants in this highly prepared group also agreed that health care workers (100%) and their families (71%) should be given antivirals. Although only one pollable question on the topic of antivirals came out of the Albany-area meeting, many facilitators noted it was an important topic. In Cortland County, participants stressed that decisions should be made by medical professional rather than politicians. Generally, groups wanted vaccines and antivirals to be used for the greater good by giving them to health care workers.

**Governmental Support**

Another need identified by participants was the ability of the government to serve the at-risk population adequately. Trust in the government was a big issue for Albany-area participants. They noted that people are treated unequally, with 60% disagreeing that the government is treating all members of the population equally in preparing for and responding to a pandemic.
Slightly less than a majority (45%) also disagreed that a person’s socio-economic standard would be taken into consideration when determining your access to care or treatment.

Participants in both the Albany area and Chautauqua County expressed concern that resources would not be distributed fairly to at-risk populations. In Chautauqua County, 62.5% agreed that a person’s status in the community would likely influence receiving scarce medical supplies and override priorities established by state guidelines. Although 50% of participants in the Albany-area meeting agreed that state resources, finances, education, vaccine and transportation would be shared proportionally based on a jurisdiction’s population, this percentage is much lower than agreement on many other questions. One table in particular expressed deep concern that the decisions about “who gets what” should not be based on their ability to pay. In addition to questioning the fairness of distribution, those in the Albany area also questioned the ability of the state government to effectively distribute food and medical supplies to all who need them. Participants were split, 32% agreed and 32% disagreed that such would happen.

Citizens in Chautauqua County also suggested that the NYSDOH or the local health department should provide a basic emergency kit for each household, including information on pandemic flu and the use of face masks, and charge residents for the kit, based on the ability to pay. A total of 87.5% of participants agreed with this suggestion; 37.5% agreed that the kit should be provided free of charge.

**Community Support**

Another need identified by participants was community support.

Participants in Cortland County indicated that support was lacking slightly, especially in the area of childcare, with 32% agreeing and 44% disagreeing that there are enough alternatives to provide care for children of single parents and keep those children safe if group daycare is not available. They suggested keeping some centers open with increased hygiene and infection control.

Participants in Albany-area, Cortland County, and Chautauqua County meetings suggested that communities need to work together to provide such support. In Cortland County, 79% agreed that in the event of a pandemic people are willing to ask for help from neighbors, friends, and other community networks. Participants in Chautauqua County (81.3%) likewise would accept, support, and perform actions to provide services/resources for the greater good, knowing that others may not receive the same services.

For the community to provide such support, people need to actively organize themselves to prepare for a pandemic. In the Albany area, 92% agreed that creating a local preparedness plan, including checklists and education at the neighborhood level is important.
In Chautauqua County, 94% agreed that communities need to organize themselves on the neighborhood level to prepare for an emergency.

**Health Care System**

Another need identified by participants is a fully-prepared health care system.

Those in the Albany area and Chautauqua County expressed that the health care system needs to be better prepared in terms of workers and supplies. Many (68%) Albany-area participants agreed that attention needs to be paid to the “aging out” of health care workers in their ability to respond in a pandemic, since the majority of those in the health care industry are over 50 years old. Those in Chautauqua County were also concerned about having prepared health care workers. Most (82%) disagreed that sick health care workers would report to work because of their concern for patients, but 87% agreed that sick workers would report to work due to financial concerns. Agreement on these issues reflects the need to address the issues regarding the health care work force during a pandemic.

Participants in Chautauqua County also were concerned over potential attempts to manipulate the health care system by patients. A total of 81% of participants agreed that patients would falsify symptoms to gain EMS transport or access to a hospital. Since resources will be in short supply during a pandemic, this issue needs to be addressed.

**Economics**

A final need identified by participants was economic security. Although there was only one pollable question offered on this topic, participants in both Nassau County and Chautauqua County expressed concern over the motivating factor of economics and people’s willingness to comply. Participants in Chautauqua County were worried about how economics would affect people’s ability to stay home from work if they were sick. Participants in Nassau County were split on whether economics would affect their decision to comply with 48% agreeing, 6% neutral, and 45% disagreeing that “economics would drive my decisions to comply with government regulations for my family’s protection.” One table was adamant that economics trumps family, friends, and even health. Another group stated they would go to work even if they were sick if they needed the money.

Employer education is needed so that all employers and workplaces have a continuity of operations plan (COOP) in effect long before a public health crisis occurs. Employer and employees need to know what the COOP calls for and how the plan will be activated. Pre-planning, training, and exercising are needed so all involved are educated and able to follow through during a pandemic.
**Personal Preparedness**

Participants also identified a few specific needs in the area of personal preparedness.

In the prepared community of Nassau County, participants suggested that individuals need to make their own decisions for themselves and their families. A total of 74% of participants agreed that their own perception of danger and/or fear would drive their decision over and above government recommendations in the event of a pandemic. This community was also split (35% agree, 35% neutral, 29% disagree) on whether they would take antivirals, vaccines, or use community mitigation measures *only* if pandemic influenza affected their local community. A total of 74% also agreed that in the event of a pandemic, it is important for every family and individual to have a healthcare proxy/living will or last will and testament in place.

While those in Nassau County advocated for very proactive personal preparedness, those in the Albany-area feared that individuals would not be personally prepared. A total of 60% agreed that there should be legal penalties for people who do not follow health recommendations during a public health emergency.

**Social Distancing:**

One area where participants expressed the ability to comply with government suggestions was social distancing.

First, participants were polled on whether they could stay away from a) the doctor’s office (unless symptoms were life threatening), b) day care centers, c) worship services, and d) other support services. In all meetings, there was a high level of agreement with people staying away from their doctor (unless symptoms were severe), day care centers, and meal sites (all above 84%). Participants in Cortland County suggested having guidelines that indicate at what point individuals should seek medical care. They also suggested establishing a helpline for phone screening and preparing a progression of symptoms chart with color-coded minor, moderate, and severe descriptions of symptoms. This would also help keep people from going to the doctor’s office unnecessarily.

There was also a high level of agreement in avoiding worship services, and support services (76.3% and above). Participants in Albany-area, Cortland County and Nassau County meetings all had high levels of support for keeping family members away from doctors or hospitals (90% or above). There was general agreement on this issue in Chautauqua County, as well, (75%).

Based on these results, it appears that social distancing is one area where participants felt they would be able to comply with official instructions, provided they fully understand what they are being asked to do and there is no economic disadvantage involved.
However, discussion revealed that participants were worried about the ability of certain populations to comply with social distancing such as the poor, chronically ill and elderly who live alone. Participants in Chautauqua County suggested creating a registry for people who live alone and have no caregivers. They also stressed that community members should start supporting other community members as well as attending self-help classes prior to a public health emergency.

E. Post Meeting Focus Group

Overall, focus group participants assessed the meeting as a highly positive experience. Their comments addressed the best part of the day as well as suggestions for what could be improved in future processes. Below is a summary of focus group participants’ comments from all meetings. Complete listings of focus group results per city are located in Appendix D.

Participants in all meetings commented that talking in small groups and sharing perspectives was the best part of the day. Albany-area participants stressed how they really enjoyed hearing “the creativity and different perspectives from all involved.” Participants in Nassau County commented that they enjoyed the ability to express themselves. In addition, participants appreciated the ability to participate in local planning and work together with the local and state governments. Participants in Chautauqua County commented that they especially liked the video presentation and the public health presenter, indicating that having an expert with good interpersonal skills can help to establish an atmosphere of trust.

The suggestion made by focus group participants echoed most across all meetings was that citizens wanted to come away from the meeting empowered to become active in their communities. They wanted information, resources, and tasks to better prepare and educate their local community about a pandemic. In short, participants wanted to leave the meeting with a charge. They also wanted the local government and community organizations to be enabled to take the lead in pandemic planning. They noted that people tend to trust these groups more and identified specific groups that can be utilized in the effort. Finally, there were some suggestions about the structure of the meeting. In Nassau County participants wanted more time to digest information while participants in the Albany-area meeting did not like the pollable ballot. They “wanted to rank all of the issues by importance to those of us in the meeting rather than vote on them.”

F. Facilitator/Note-taker Evaluation Questionnaire

The facilitators and note-takers were presented a series of questions on the diversity of participants, what worked best in their groups, what could be improved and what lessons they learned. Complete listings of the responses are located in Appendix E.
Generally, facilitators and note-takers reported a fairly diverse, educated, and engaged audience. They stated that people “worked very hard all day, [they were a] very positive group, [and] focused on solutions to problems raised and suggestions.”

Facilitators and note-takers had positive reviews of the meeting format. They thought that it worked well for getting the information needed. They especially liked the small group discussions, stating that this allowed “groups [to] work at their own pace.” The format also kept people interested and generated creativity. However, a number of facilitators commented that in the future, rooms should be chosen that provide adequate size and that allow for engagement without distraction or high noise levels in the room that interfere with facilitating the discussion.

When addressing what could be improved during the day, facilitators and note-takers were split on their assessment of the polling process. Some commented that this was the best part of the day, while others thought the process took too long and that people were tired at this point and unable to fully focus on the complexity of all the pollable issues being presented. Other areas for improvement included having more time for activities like trust-building exercises and making sure that materials are written clearly, in “plain” English at an appropriate reading level and made available to the facilitators/note-takers as early as possible before the meeting.

The biggest lesson learned, noted by facilitators and note-takers, was the need to give participants something to take away from the meeting. Now that participants felt empowered, they wanted to do something. Another lesson learned was the issue of recruitment. Participants were supposed to represent both at-risk consumers and their advocates. In Nassau County one facilitator noted that the group appeared very prepared and did not represent an at-risk population. A final lesson learned was the challenge of keeping people focused during a long day of information and in-depth discussion. However, also in Nassau County one participant indicated that given the gift card, quality of food, and importance of the discussion, the meeting should have continued another few hours rather than end in the early afternoon!

VI. Conclusion

On April 12, 2008, approximately 120 diverse at-risk consumers and advocates met together to discuss the needs of at-risk populations and help health officials improve preparedness goals. They became better informed on pandemic issues, with pre-and post-tests showing significant increases in knowledge. During the day, the themes of trust, stockpiling, importance of becoming active in the community, and self-reliance emerged. Through polling and discussion participants identified nine specific areas of need for at-risk populations during a pandemic. In summary, these are:
1. Stockpiling: Participants are confident in their ability to stockpile food, essential supplies and medicine if they are given information about how to do this and what items are needed. Regulations need to be adapted to support/allow storage of prescription medications. In addition, plans must be made to help those in the community for whom stockpiling might be difficult.

2. Access to Quality Information: Information about all aspects of pandemic planning should come from health care providers, help-lines, and community and governmental leaders.

3. Medication: Participants’ willingness to take and give medication that might help them but has not been proven safe would hinge on whether the benefits outweigh the risks, especially concerning children.

4. Governmental Support: Every level of government must build capacity and demonstrate that all people are being treated fairly in terms of pandemic planning and preparedness.

5. Community Support: Communities should begin active planning by drawing on interested individuals and networks to provide necessary education, support, and resources, especially relating to childcare and provision of essential supplies.

6. Health Care System: The health care system must address issues of aging workers and the policy for staff retention during a pandemic.

7. Economics: Economics as a motivating factor for compliance to public health guidance must be examined.

8. Personal Preparedness: Individuals must be motivated to become prepared.

9. Social Distancing: Individuals must be informed about what they would be asked to do in the event of a severe Individuals for whom complying with social distancing might pose a hardship need to be identified in advance and alternatives devised.
Appendix A: Agenda

7:30 – 8:50  Registration/Continental Breakfast

8:50 – 9:00  Pre-Meeting survey  Keystone

9:00 – 9:20  Welcome /Opening Remarks / Overview  Local, NYSDOH and Keystone

9:20 – 10:00  Background: Pandemic Influenza Overview  DVD-Video
• Q&A on Pandemic Influenza and at-risk populations  Keystone

10:00 – 10:15  Break

10:15 – 10:20  Directions to Break Out Groups  Keystone

10:20 – 12:30  Break Out Group Discussions  Facilitators

12:30  Working Lunch  All
•  Note: Facilitator/Note-takers meet with Keystone staff to share 1-2 pollables

1:00 – 2:20  Break Out Group Discussion *(continued)*  Facilitators

2:20 – 2:40  Breakout Group Report-Out  Facilitators

2:40 – 3:00  Paper Ballot Polling  Keystone

3:00 – 3:15  General Discussion, Questions & Answers  Keystone, All

3:15 – 3:30  Wrap Up and Next Steps  NYSDOH

3:30  Adjourn

Post Meeting Activities

3:30 – 3:45  Post Meeting survey  All

3:45 – 4:15  Participant Focus Group and Facilitators Debrief Survey  Participants and Keystone
Appendix B: Transcribed Questions and Answers from Meetings

Albany-area

Jim Kirkwood, Epidemiologist, New York State Department of Health

Q: For people who live paycheck to paycheck, how can they be prepared and stockpile food and necessities?

A: Begin to stockpile a little food at a time and remember it is non-perishables that should be stockpiled with the understanding that they too need to be replaced periodically as well.

Q: It is unrealistic for some households to stockpile food—what about food pantries? Can’t they stockpile and share food with people who cannot afford to stockpile?

A: There are groups that are focusing on food and water. Work with your local health department and stock a little at a time. Focus on the important things, water and appropriate canned goods that are highly nutritionally in value. Your local health department can provide information and a checklist.

Q: If people have to stay at home and cannot get their prescriptions for more than 30 days at a time, the regulatory barriers will hurt people—will the government consider changing these barriers?

A: The state and federal government are well aware of these issues and are talking about how to overcome them during a public health emergency.

Q: What about RX like Ritalin that are federally restricted and cannot be prescribed for more than 30 days at a time?

A: Ask your health care providers and doctors about their pandemic planning and how they might work with you when there is an emergency. They need to plan now as well and when you ask them for information on their planning they should be in a place to discuss their own planning with their patients.

Q: What are the minimum and appropriate nutritional values required to stockpile?

A: A two-week supply of non-perishable food is the minimum. Talk to your own doctor as the nutritional value required for children and elderly vary greatly. If your own doctor cannot help then contact your local public health agency who will have a nutritionist who can help create a short list of canned and non-perishable foods to have in your household.
Q: What if you have no electricity or power and you need refrigeration for your medicines? What happens to the homeless? What if you need a Service Provider and they cannot get to you to help?

A: Ask your provider what they are doing to prepare. Most utility companies have a Continuity of Operations Plan (COOP) that they will follow. Backup generators will be used. Talk to your pharmacist as well about the shelf life of your medicines.

Q: Why aren't we hearing about what our grandmothers used—good old bleach—as a disinfectant to help kill germs?

A: A 1% solution of bleach is very effective to clean and kill germs. There are many “green” cleaners that are just as effective.

Q: What should people who are out of town (on vacation/on a trip, etc.) do about meds and being prepared?

A: Plan ahead and take your medications with you. Hopefully you’d be able to get home before your medications run out or you could call your pharmacist to transfer your RX. If you are going to be gone for an extended period of time ask your doctor to give you a new RX to have with you.

Q: What will happen if businesses are closed and people don’t get their paychecks? Will there be any federal subsidies?

A: The federal government has made allowances in the past and likely in a public health emergency the federal and state government might step in. Ask your employer now if they have a plan and how they might work with you if you had to remain at home for an extended period of time.

Q: How does the virus develop?

A: A virus mutates and like avian flu which generally cannot transfer from animals to humans a virus has been known to mutate and change so that in the future it might easily transfer from a bird to a human and then human to human. This is our concern that when it happens it will spread widely and quickly due to the mobility of society today.

Q: How quickly could it spread?

A: Very quickly!
Q: What is the difference between epidemic and pandemic?

A: Epidemic is an outbreak that spreads quickly, and the seasonal influenza is sometimes an epidemic and it is present every year. A pandemic is a widespread epidemic that is more severe than the seasonal influenza and affects people in many different countries around the world.

Q: What happens when the mobile food services which support many homebound people cannot provide food services to these people?

A: The American Red Cross is already considering how to handle these types of situations.

Q: How about people who do not speak English? How will they be informed?

A: The local and state health departments are already working with the media outlets in preparing bilingual broadcast and media marketing materials.

Q: There will likely be many deaths and corpses. What will happen with the bodies?

A: The health department is already working with the morticians and funeral director associations to be prepared for mass fatalities.

Q: What about young children and WIC food stamp program?

A: Health department is working on a toolkit for childcare preparedness during a pandemic. Same is true for preparing elderly and working with people who will be stressed. Checklist and informational booklets are needed and being prepared.

**Cortland County**

*William Maliha, M.D., Medical Director, Healthcare Emergency Preparedness Program, New York State Department of Health*

Dr. Maliha suggested that participants ask for samples of medications from doctors. He answered following participants’ questions:

Q: I live in senior building, president of facility; we ask people to stay in their rooms when they are sick but people don’t – how can this be prevented?

A: There is not going to be martial law because of democracy, we have to ask people. Ask for this to be discussion topic on the next meeting. Spread the information, and let them know why it’s important for people to stay inside if they are sick; give them websites.
Q: People don’t believe that there is going to be pandemic in my groups; how can I tell people to be worried and that it is not a game?

A: Society historically doesn’t listen. Websites show pictures of previous pandemics. Send people to sites, share articles from magazines, newspapers; pass out pamphlets; educate others; help to focus people on what has happened in past.

Q: In meeting there is an assumption that everyone has a computer and that’s not true; prescriptions only give 30 days, how do you get this from your insurance company?

A: Libraries can help you look up the information; go to health departments; medications – they are talking about working with insurance companies, but don’t plan on it; squeeze out extra days from medications; go to doctors and get samples; some of the medications cost less than co-pay – water pills may cost less than the co-pay – ask the pharmacist and ask what it is out of pocket compared to with insurance; Wal-Mart gives some of the prescriptions for free or for less.

  o Audience member comment - Most insurance will give three months if you ask your doctor – try to get ahead if you can.

Q: What do you do when you don’t get paid sick time? It’s a deterrent from people staying home if they get sick; could there be a policy for unemployment insurance if people get the flu?

A: Not everyone can work from home, if it were to get that bad, government might step in.

Q: Church facilitates numerous groups. Head Start is one of them. What is the process of notification if pandemic hits?

A: Once the first or second wave hits, CDC will go on alert and there will be several weeks notice. When it gets to US, Canada or Mexico, word will get out immediately. State measures will start immediately once it gets into a state; the problem is that disease moves quickly; they will notify through various media sources.

Q: There is a concern with closing child care and with rural areas. How care will that happen for these areas; there is concern for single parents without access to aid.

A: Part of message today is to think about emergency networks that can start being discussed today. We need to have neighbors/friends that will pick up the phone or drive out and check on people; planning/ thinking ahead. We must plan for temporary breakdowns; plans with those around you; think back to planning for nuclear war – people stockpiled - it’s possible.
Q: With no historical perspective – what things were done with the last pandemics to make them less severe?

A: Good question. One occurred during a school break/holiday. Society is healthier; there are antibiotics for bacteria infections. We have more modern conveniences which have helped; viruses could have been different.

Q: Individuals are smart, but collectively, aren’t. How do you stop the panic of an outbreak?

A: We will have a time lead; use of information; public service announcements; explanations of how to protect ourselves. If there is social disorder, then police have a role; breakdown of services won’t be permanent. Stores might have different hours; things will be different, but society will still continue; rural – churches should be involved with networking.

Q: Will the county use reverse 911 to send updates and information?

A: FCC has initiated and approved to send mass alerts also on cell phones; text messages; internet messages.

   o Brenda DeRusso (facilitator/note-taker) – emergency management – better program than reverse 911 – New York Alert – for it, go to library, friend’s house. You can tell the system how you want to be notified of an emergency; can pinpoint the info that you want (weather, terrorist attack, health issues); www.NYAlert.gov.
   o NYSDOH will also work to communicate through this process.

Q: Can we get a copy of the movie to share with others?

A: Pam Griffith answered: Cortland County has copies and will be it showing in different settings, working with businesses on issue; have a committee.

Q: Is reverse 911 still in effect?

A: Brenda DeRusso answered: Until June 1st. Then on June 2nd, the lists will be transferred to NY Alert; same capability of reverse 911; NY Alert will be able to make a circle around the geographic area and communicate with people so if you don’t have a land line, you need to enroll. Raising the education level is key.

Q: What’s the worst case or likeliest case?

A: Ranges have been created – 15%-40% infected; when it mutates into a form that attacks humans, it will become weaker. But, we can’t predict accurately so going by past pandemics; severity can’t be answered; on the worst end, but not the worst.
Dr. Maliha – answered questions about water, storing water, water containers and types of non-perishables.

Q: What about masks?

A. Two types of masks – surgical – will prevent someone that is contagious to protect others from their germs; fitted masks/dust masks (use in construction) – better level of protection, but must fit properly – can buy at tool shops, Wal-Mart.

Chautauqua County
Gregory Young, M.D. is with the NYSDOH Western Regional Office

Q: Dr. Young indicated that the next epidemic will start in the Orient, how do we know it won’t start locally?

A: Viruses are carried by waterfowl. Birds, pigs and people (all in close proximity) are needed to start a pandemic. Asians have closer contact with birds and pigs. It could start somewhere else though; there's just a greater likelihood of it starting in Asia.

Nassau County

Q: Mask wearing during pandemic?

A: Personal protection – such as hand washing, covering mouth when sneezing, staying away from crowds measures – are the first line of defense that will be relied on to limit spread of pandemic flu. Understand that masks may not be available for all and, further, that only “fit tested” masks are effective against the small, viral particles of which pan flu is composed.

Q: Radio and TV’s ability to “spread the word” during a pan flu outbreak?

A: In the beginning of an outbreak, the media will be available to alert the public during the beginning of an outbreak. However, if the outbreak is really severe, media services will be compromised as their staffs become ill and aren’t able to operate the media outlet.

Q: One station that operates during a severe outbreak. Will there be one station to broadcast?

A: Most likely, yes. That’s where you’ll hear it in the beginning, at least.

Q: Flu season?

A: Generally, the flu occurs during the winter months, but not always. This year, for example, the flu started in January and continues through this month (April). So, really, flu season can occur anytime.
Q: Wearing gloves as a protective measure?

A: That’s a good personal protection measure, as is using hand sanitizer regularly.

Q: DVD mentioned throwing out tissue, but not washing hands after throwing away tissue. [Participant is in error. The DVD says and shows a man who throws away tissue and then uses hand sanitizer afterwards].

A: True. You should always wash hands after tissue use.

Q: Is most flu spread by birds?

A: Not necessarily. Bird flu doesn’t always make the jump from bird-to-bird transmission to bird-to-human transmission.

Q: We have lots of geese in area.

A: Pandemic influenza occurs once the virus has mutated into a form that’s contagious to humans. There’s rarely a link between geese and human infections. The bird flu, at least in USA, does not always jump to humans.

Q: How does medical community determine when its time to declare a pandemic influenza outbreak?

A: Medical professionals consider a variety of factors in their assessment of whether a pandemic influenza outbreak is about to occur. These factors include the rapidity with which it the virus spreads, the virulence of the strain. There is panel of experts on pan flu who take these and others factors before declaring an outbreak.

Q: Can’t really carry enough hand sanitizer around to use every time you cough, blow nose, throw tissue away.

A: If you’re so sick that your can’t carry enough sanitizer to use every time you sneeze, cough or blow your nose, then you probably shouldn’t be walking around.

Q: Is 1918 Spanish Flu still active?

A: There were two strains of that flu. Both were harvested from corpses of Marines found frozen above the Arctic Circle. They were living in close quarters. That’s how it spread. The virus is in a laboratory and is not circulating now. The Spanish Flu virus was a combination of avian and bovine virus.
Q: Millions of folks choose to not get vaccinated.

A: True. But each year there’s a little bit fewer folks who refuse vaccinations. Seniors with Medicare are tracked and the number of them getting vaccines is slowly increasing each year.

Q: Who decides how to distribute vaccines?

A: CDC developed its guidelines for the distribution of vaccination in consultation with people like you who participated in forums like this one. They, like you will, helped shape the CDC’s guidelines. CDC and your local health departments often rely on community input to shape guidelines. Your input today is important to us.

Q: Does getting flu shot help against pandemic influenza?

A: No. Because pandemic influenza is entirely different from previous known influenza viruses, humans don’t have any immunity from it. Experts around the world forecast which influenza virus is mostly likely to appear during the coming influenza season. Usually, this forecast is accurate and there’s enough lead-time to develop and test the appropriate vaccine. However, with pandemic influenza, the forecast is wrong and no vaccine has been prepared.

Q: I volunteer at a nursing home where there was no soap in the restroom. Owners said the residents steal it. I said put it on the wall. Also, see waitresses combing hair without washing hands. Maybe we should tell such folks that they need to wash hands.

A: What both of these anecdotes underscore is the need for you and others to take the initiative when you see unsafe practices. It is your personal initiative that will have the biggest impact in curbing the spread of pandemic influenza.

Q: I don’t remember last pan flu. Maybe I was too busy raising my family to notice. But can the current concern about pandemic influenza be attributed to the huge role the media plays keeping us informed nowadays?

A: Yes, the media is everywhere now; they get the word out broadly and often. Plus, we travel more easily and more frequently now. This aids in spread of virus.

Q: While information moves more quickly now, there also seems to be more inaccurate and unfounded information out there that can lead to a “scare” or create a hoax.

A: Medical experts’ knowledge base and expertise on pandemic influenza is really strong now. These experts generally well regarded by the local health professionals who know how to rapidly get the accurate word out to there communities. Local medical professionals are well-prepared to get the right information about pandemic influenza and alert their communities effectively.
Q: Is avian flu more lethal than past influenzas on record? I have noticed a lot of effort to deal with it.

A: In countries where poultry is part of household, there are cases on bird-to-human transmission. But, in these countries, there is seldom human-to-human transmission.

Q: I am skeptical about governments’ willingness to get the word out because of fear their fear of being seen as unprepared to manage an outbreak.

A: Medical professionals and managers have learned much from past attempts by public officials to cover up influenza incidents and other public health threats. The Harvey Finkelstein case in 2007 provided a lesson that New York’s current health commissioner learned. That case emphasized the need to improve communication. As a result, NYSDOH will be quicker to identify viruses and get the word out efficiently. In fact, government at all levels is now prepared to mobilize ASAP.

Q: What is the incubation time for the influenza virus and how long does it take for a vaccine to provide protection?

A: The incubation period is a few days. The vaccination takes two weeks to provide protection.

Q: What about garbage collection?

A: That’s definitely a huge question.
Appendix C: Transcribed Note Cards

Participants had an opportunity to submit questions on note cards.

Albany area

1. Needs to be some process for emergency precautions, out of town, cruises.

2. Information in as many forms as possible, audio, Braille, etc., large print.

3. I think that the local level best. Local level is fire districts/ departments/ local EMS for mobilization. Group most people trust.

4. What will happen to people who are incarcerated? Are they allowed to go home?

5. At the time of vaccine dissemination, what is the protocol? Seasonal flu- typically vaccinate older and younger. Is that the same protocol in this pandemic?

6. Can physician samples be used for back up for planning?

7. Phones won’t work in power outage. Only old phones work.

8. There should be a method of marking homes when there is an active case of flu in a home.

9. There is some temporary housing for homeless people; however it is usually a large room accommodation which many people must share. Can they seek temporary shelter?

10. Please take into consideration people with mental health problems who live in private housing—they do not necessarily interact with neighbors/communities. Access to information and help.

11. Focus on good health habits now- old school healthy food to boost immune system so in better shape when flu hits.

12. Medication manufactured overseas an issue—most of our meds. Manufactured out of U.S.

13. Information-handouts should be bulleted so people can use it like a cookbook index. Otherwise, people will not use the information if they have to read too much.

14. Closed caption DVD is difficult to read.
15. How does Family Medical Leave Act (FMLA) factor into a pandemic and extended time away from work? (For after the flu)

16. What do we do with the dead bodies if everyone is home?

17. What mental health (MH) services will be available for the rest of the pandemic?

18. Is there a triage list of essential services? Where you would know ahead of time whether you would go to work?

19. All existing disaster plans call for the county DOH to handle medically needy persons in the event of a sheltering emergency. With an isolated event, hospitals and nursing attention has sufficed. In a pandemic or region wide emergency, the hospitals won’t be available and allocating nurses to one or two home care patients would not be in the country’s best interest.

20. Should we mandate all pharmaceutical companies to produce/develop vaccine/antivirals?

21. Will there be travel restrictions when infected (state-to-state) quarantine?

22. Scope of practice Issues when patient need overwhelms available resources (RN’s expanded practice, etc.); Health care workers are getting older. Current plans to care for mass numbers of patients all include cots that are very low to the ground. Haw’s ability to bend and get back up is getting more limited. Long hours also not conducive to older workers.

23. Can we use private organizations such as K of C to help with first-to second wave?

24. Security protection for those who administer a scarce resource, vaccine or anti-virals. In our rural county, state police oversee the county nurses, but hospital staff are on their own.

25. Use of medications—back up reserve vs. throwing away? Recently in news.

26. How long is water bottled in plastic “good”?

27. What about public education, does the general public understand this will happen? (So the public will buy into the idea and prepare.)

28. How quickly would the general public be made aware to initiate measures in the event of pandemic flu?
Cortland County
1. After all this information is put together will we be getting a booklet, pamphlet, etc?

2. Drugs that are individually wrapped and assigned to nursing home patients - Are they discarded or available to redistribute?

Chautauqua County
1. Aging population- alone who will care for them. Identified. Registry for aging through physicians. Immigrant agency—prepare. Medical supplies, priority list, control symptoms. Ventilators—ethics committee. Will there be mental health available? Religious leaders- decision makers on ethics. Do expect treatment- as long as there is informed consent- then yes. In a desperate effort willing to take.

2. Personnel shortage—what decides whether you report to work on care for your own family/ community? Where is the greatest need?

3. Public information—how are people getting it?

4. Suggestions: When Ed does initial intro, turn off slide show so it won’t be distracting from what he has to say. Evenly distribute participants to tables to avoid groups varying from 8 people to 3 people.

5. Home health care needs to be included in grant “seed money” opportunities. How long does water store?

6. Liability for HCU that want to help neighbors/friends in the event of pandemic. Challenge- coordination of care for patients in the community- HHA points and multiple medical resources needed.

7. Swing seminars, etc.; create a sign-up sheet with contact information to create a network directory.

8. The program was very interesting and informative and should be helpful to appropriate state agencies. However, I expected it to be more helpful in preparing me to assist my local community in readying for a pandemic.

Nassau County
1. Local and county health department and information is perceived by locals as more trustworthy and reliable than information from state and/or federal officials.

2. Young people should be more educated on the importance of avoiding crowds (i.e., social distancing), in the event of a pandemic.
3. Insurance companies should allow individuals to have two-week supply of daily prescription medications on hand.

4. I would be willing to take antivirals, vaccines or use community mitigation measures only if pandemic influenza affected my local community.

5. Economics should drive my decisions to comply with government regulations for me and my family’s protection.

6. My perception of danger and/or fear will drive my decisions over government recommendations in the event of pandemic influenza.

7. In the event of pandemic influenza, my local government should send messages as they are the most trusted leaders in my community.

8. In the event of pandemic influenza, antivirals should be targeted to the high-risk groups most affected by a pandemic.

9. In the event of pandemic influenza, health care workers and first responders should receive antivirals for prophylaxis.

10. In the event of pandemic influenza, consideration should be given to providing health care workers’ families with antivirals.

11. In the event of a pandemic influenza, it is important for every family and individual to have a healthcare proxy or will in place.
### Appendix D: Polling Results

(1 = definitely would / strongly agree, 2 = Might / Agree, 3 = I do not know / Neutral, 4 = I might not / Do not agree, and 5 = I definitely would not / Disagree.)

<table>
<thead>
<tr>
<th>Appendix D: Polling Results</th>
<th>Cortland</th>
<th>Albany</th>
<th>Nassau</th>
<th>Jamestown</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) During a pandemic, if you got sick, how likely would you be to follow instructions to stay away from hospitals or doctors’ offices unless your symptoms were truly life threatening?</td>
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<tr>
<td>Agree</td>
<td>94.50%</td>
<td>97.40%</td>
<td>93.50%</td>
<td>93.70%</td>
</tr>
<tr>
<td>Disagree</td>
<td>3.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Neutral</td>
<td>0.00%</td>
<td>2.60%</td>
<td>6.50%</td>
<td>6.30%</td>
</tr>
<tr>
<td>b) During a pandemic, if someone in your family got sick, how likely would you be to follow instructions to stay away from hospitals or doctors’ offices unless their symptoms were truly life threatening?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>94.10%</td>
<td>94.10%</td>
<td>90.30%</td>
<td>75.00%</td>
</tr>
<tr>
<td>Disagree</td>
<td>5.90%</td>
<td>3.30%</td>
<td>9.70%</td>
<td>18.70%</td>
</tr>
<tr>
<td>Neutral</td>
<td>0.00%</td>
<td>2.60%</td>
<td>0.00%</td>
<td>6.30%</td>
</tr>
<tr>
<td>c) During a pandemic, if you are directed to stay away from crowded places, how likely would you be to avoid day care centers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>97.00%</td>
<td>86.80%</td>
<td>100.00%</td>
<td>100.00%</td>
</tr>
<tr>
<td>Disagree</td>
<td>3.00%</td>
<td>7.90%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Neutral</td>
<td>0.00%</td>
<td>2.60%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>d) During a pandemic, if you are directed to stay away from crowded places, how likely would you be to avoid worship services?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>100.00%</td>
<td>78.90%</td>
<td>93.50%</td>
<td>81.20%</td>
</tr>
<tr>
<td>Disagree</td>
<td>0.00%</td>
<td>5.20%</td>
<td>6.50%</td>
<td>6.30%</td>
</tr>
<tr>
<td>Neutral</td>
<td>0.00%</td>
<td>7.90%</td>
<td>0.00%</td>
<td>12.50%</td>
</tr>
<tr>
<td>e) During a pandemic, if you are directed to stay away from crowded places, how likely would you be to avoid meal sites?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>97.00%</td>
<td>84.20%</td>
<td>93.50%</td>
<td>93.80%</td>
</tr>
<tr>
<td>Disagree</td>
<td>3.00%</td>
<td>5.30%</td>
<td>6.50%</td>
<td>6.20%</td>
</tr>
<tr>
<td>Neutral</td>
<td>0.00%</td>
<td>10.50%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>f) During a pandemic, if you are directed to stay away from crowded places, how likely would you be to avoid other support services?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>83.30%</td>
<td>76.30%</td>
<td>87.20%</td>
<td>100.00%</td>
</tr>
<tr>
<td>Disagree</td>
<td>16.70%</td>
<td>7.90%</td>
<td>6.40%</td>
<td>0.00%</td>
</tr>
<tr>
<td>Neutral</td>
<td>0.00%</td>
<td>13.10%</td>
<td>6.40%</td>
<td>0.00%</td>
</tr>
<tr>
<td>g) During a pandemic, given that there may not be enough lifesaving medication to go around, do you agree/disagree that certain groups of people should be treated before other groups of people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>91.20%</td>
<td>78.40%</td>
<td>96.80%</td>
<td>87.50%</td>
</tr>
<tr>
<td>Disagree</td>
<td>8.80%</td>
<td>8.10%</td>
<td>3.20%</td>
<td>12.50%</td>
</tr>
<tr>
<td>Neutral</td>
<td>0.00%</td>
<td>13.50%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>h) Do you agree or disagree that certain groups of people should be treated before other groups of people even if that means that supplies might run out before you can get the medicine you need?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>88.20%</td>
<td>86.90%</td>
<td>93.50%</td>
<td>87.50%</td>
</tr>
<tr>
<td>Disagree</td>
<td>8.80%</td>
<td>7.90%</td>
<td>6.50%</td>
<td>6.20%</td>
</tr>
<tr>
<td>Neutral</td>
<td>3.00%</td>
<td>5.30%</td>
<td>0.00%</td>
<td>6.20%</td>
</tr>
</tbody>
</table>

| i) During a pandemic, how likely would you be to accept a medication for yourself that the medical profession strongly believes would help you and/or be lifesaving, but is not fully proven to be both safe and effective? |
|---|---|---|---|
| Agree | 82.30% | 76.00% | 67.70% | 94.80% |
| Disagree | 8.80% | 15.80% | 16.10% | 6.20% |
| Neutral | 1.20% | 7.90% | 19.30% | 0.00% |

| j) During a pandemic, how likely would you be to accept a medication for your children that the medical profession strongly believes would help you and/or be lifesaving, but is not fully proven to be both safe and effective? |
|---|---|---|---|
| Agree | 76.50% | 60.50% | 64.50% | 87.50% |
| Disagree | 14.80% | 26.30% | 22.60% | 12.50% |
| Neutral | 5.90% | 10.50% | 12.90% | 0.00% |

| k) If you were told to do something that will pose an extreme hardship, which source would you rely on for trustful information? |
|---|---|---|---|---|
| Government Official | 11.80% | 7.90% | 6.40% | 25.00% |
| Health Care Provider | 58.80% | 44.70% | 54.80% | 37.50% |
| Faith Leader | 0.00% | 7.90% | 0.00% | 0.00% |
| Community Leader | 11.80% | 7.90% | 16.10% | 18.80% |
| Media Resource | 0.00% | 7.90% | 3.20% | 6.20% |
| Health Hotline | 20.50% | 10.50% | 16.10% | 12.50% |
| The Internet | 3.00% | 10.50% | 3.20% | 0.00% |

| l) In advance of an emergency like a pandemic, how likely will you be to stockpile at least a 2-week supply of non-perishable food and emergency supplies? |
|---|---|---|---|---|
| Agree | 91.20% | 89.50% | 96.80% | 93.80% |
| Disagree | 3.00% | 2.60% | 0.00% | 6.20% |
| Neutral | 6.00% | 5.30% | 3.20% | 0.00% |

| m) In advance of an emergency like a pandemic, how likely will you be to stockpile at least a 2-week supply of bottled water? |
|---|---|---|---|---|
| Agree | 91.20% | 84.20% | 83.90% | 87.50% |
| Disagree | 3.00% | 7.90% | 9.70% | 6.30% |
| Neutral | 5.90% | 5.30% | 6.40% | 6.30% |

| n) In advance of an emergency like a pandemic, how likely will you be to stockpile at least a 2-week supply of the medicines you take regularly? |
|---|---|---|---|---|
| Agree | 88.20% | 89.50% | 96.80% | 80.00% |
| Disagree | 8.80% | 7.90% | 0.00% | 13.30% |
| Neutral | 0.00% | 7.90% | 3.10% | 6.70% |
### Additional Proposed Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Disagree</th>
<th>Neutral</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Do you agree or disagree that basic background community education on pandemic influenza is needed so communities and all people can prepare individually and at a local level?</td>
<td>89.50%</td>
<td>5.30%</td>
<td>2.60%</td>
</tr>
<tr>
<td>2) Do you agree or disagree that state resources, finances, education, vaccine priorities and transportation will be shared equally based on geographic population?</td>
<td>50.00%</td>
<td>23.70%</td>
<td>26.30%</td>
</tr>
<tr>
<td>3) Do you agree or disagree that attention needs to be paid to the “aging out” of health care workers and their ability to respond in a pandemic?</td>
<td>68.40%</td>
<td>18.40%</td>
<td>7.90%</td>
</tr>
<tr>
<td>4) Do you agree or disagree that a persons socio-economic standard is taken into consideration when determining your access to care or treatment?</td>
<td>29.00%</td>
<td>23.70%</td>
<td>44.80%</td>
</tr>
<tr>
<td>5) Do you agree or disagree that the government should provide more incentives to all pharmaceutical companies to produce/develop vaccine/antivirals?</td>
<td>68.40%</td>
<td>13.20%</td>
<td>18.40%</td>
</tr>
<tr>
<td>6) Do you agree or disagree that a process should be put in place to eliminate regulatory barriers to accessing prescriptions medicines during a pandemic.</td>
<td>81.60%</td>
<td>7.90%</td>
<td>5.30%</td>
</tr>
<tr>
<td>7) Do you agree or disagree that individuals know enough about what they need to stockpile in their homes to be prepared for a pandemic?</td>
<td>15.80%</td>
<td>2.70%</td>
<td>68.40%</td>
</tr>
<tr>
<td>8) Do you agree or disagree that people need to be educated about nutritional value of foods that they should stockpile in their home?</td>
<td>81.60%</td>
<td>13.20%</td>
<td>5.30%</td>
</tr>
<tr>
<td>9) Do you agree or disagree that your household has stockpiled enough food and water for a two week period to be prepared.</td>
<td>50.00%</td>
<td>7.90%</td>
<td>42.00%</td>
</tr>
<tr>
<td>10) Do you agree or disagree that government is treating all members of the population equally in preparing and responding to a pandemic?</td>
<td>26.30%</td>
<td>21.00%</td>
<td>57.90%</td>
</tr>
<tr>
<td>11) Do you agree or disagree that health officials should educate people about ways to improve their immune system so their body is prepared to fight a pandemic flu virus?</td>
<td>73.70%</td>
<td>10.50%</td>
<td>7.90%</td>
</tr>
<tr>
<td>12) Do you agree or disagree that there should be legal penalties for people who do not follow health recommendations during a public health emergency?</td>
<td>57.90%</td>
<td>23.70%</td>
<td>18.40%</td>
</tr>
<tr>
<td>13) Do you agree or disagree that creating a neighborhood/ community public health plan including creating check lists, neighborhood education planning is important?</td>
<td>92.10%</td>
<td>2.60%</td>
<td>5.30%</td>
</tr>
<tr>
<td>14) Do you agree or disagree that the state government has the ability to effectively distribute food and medical supplies to all who need them</td>
<td>31.60%</td>
<td>5.30%</td>
<td>31.60%</td>
</tr>
<tr>
<td>15) Do you agree or disagree that resources for pan flu planning should be prioritized for care providers, (e.g. family care providers, physicians, nurses and related medical providers)?</td>
<td>73.70%</td>
<td>13.20%</td>
<td>7.90%</td>
</tr>
</tbody>
</table>
### Cortland County

<table>
<thead>
<tr>
<th>Agree</th>
<th>Disagree</th>
<th>Neutral</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) In the event of a pandemic people will be willing to ask for help from neighbors, friends and other community networks.</td>
<td>79.40%</td>
<td>14.70%</td>
</tr>
<tr>
<td>2) There are enough alternatives to provide care for children of single parents and keep those children safe, if all daycare is shutdown.</td>
<td>32.30%</td>
<td>23.50%</td>
</tr>
<tr>
<td>3) In a pandemic, if you knew what supplies were needed and where to get them, you would be willing to take care of a loved one at home.</td>
<td>100.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>4) In a pandemic, if there were clear guidelines explaining at what point in the illness you or the person you are caring for should seek medical care, you would follow the guidelines.</td>
<td>73.50%</td>
<td>3.00%</td>
</tr>
</tbody>
</table>

### Nassau County

<table>
<thead>
<tr>
<th>Agree</th>
<th>Disagree</th>
<th>Neutral</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Local and county health department and information is perceived by locals as more trustworthy and reliable than information from state and/or federal officials.</td>
<td>77.40%</td>
<td>16.10%</td>
</tr>
<tr>
<td>2. Young people should be more educated on the importance of avoiding crowds (i.e., social distancing), in the event of a pandemic.</td>
<td>77.40%</td>
<td>16.10%</td>
</tr>
<tr>
<td>3. Insurance companies should allow individuals to have two-week supply of daily prescription medications on hand.</td>
<td>93.50%</td>
<td>3.20%</td>
</tr>
<tr>
<td>4. I would be willing to take anti-virals, vaccines or use community mitigation measures only if pandemic influenza affected my local community.</td>
<td>35.50%</td>
<td>35.50%</td>
</tr>
<tr>
<td>5. Economics should drive my decisions to comply with government regulations for me and my family’s protection.</td>
<td>48.40%</td>
<td>6.40%</td>
</tr>
<tr>
<td>6. My perception of danger and/or fear will drive my decisions over government recommendations in the event of pandemic influenza.</td>
<td>74.20%</td>
<td>6.40%</td>
</tr>
<tr>
<td>7. In the event of pandemic influenza, my local government should send messages as they are the most trusted leaders in my community.</td>
<td>67.80%</td>
<td>22.60%</td>
</tr>
<tr>
<td>8. In the event of pandemic influenza, anti-virals should be targeted to the high-risk groups most affected by a pandemic.</td>
<td>87.10%</td>
<td>6.40%</td>
</tr>
<tr>
<td>9. In the event of pandemic influenza, healthcare workers and first responders should receive anti-virals for prophylaxis</td>
<td>100.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>10. In the event of pandemic influenza, consideration should be given to providing healthcare workers’ families with anti-virals.</td>
<td>71.00%</td>
<td>19.30%</td>
</tr>
<tr>
<td>11. In the event of a pandemic influenza, it is important for every family and individual to have a healthcare proxy or will in place.</td>
<td>74.20%</td>
<td>29.00%</td>
</tr>
<tr>
<td>Jamestown (Chautauqua County)</td>
<td>Agree</td>
<td>Disagree</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------</td>
<td>----------</td>
</tr>
<tr>
<td>1) Symptomatic health care workers should report to work because of their concern about vulnerable patients at home or in nursing homes receiving adequate care.</td>
<td>18.70%</td>
<td>0.00%</td>
</tr>
<tr>
<td>2) Symptomatic health care workers should report to work because of personal financial concerns.</td>
<td>0.00%</td>
<td>13.30%</td>
</tr>
<tr>
<td>3) Patients will falsify symptoms to gain EMS transport or access to a hospital.</td>
<td>81.20%</td>
<td>6.30%</td>
</tr>
<tr>
<td>4) Persons in the community would better accept vaccine/medication prioritization if they received education about how it will improve the function and safety of the community as a whole.</td>
<td>100.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>5) A person’s status in the community would likely influence receiving scarce medical supplies and override priorities established by state guidelines.</td>
<td>62.50%</td>
<td>12.50%</td>
</tr>
<tr>
<td>6) Neighborhoods need to organize themselves in order to prepare for an emergency.</td>
<td>93.80%</td>
<td>6.30%</td>
</tr>
<tr>
<td>7) The government (federal, state, local) is responsible to deliver the information, rather than the citizens seeking out the information themselves.</td>
<td>93.80%</td>
<td>6.30%</td>
</tr>
<tr>
<td>8) Other organizations (i.e., churches, soup kitchens, grocery stores) should be involved in delivering the preparedness message and information.</td>
<td>86.70%</td>
<td>6.30%</td>
</tr>
<tr>
<td>9) The current system allows for persons and agencies to stockpile medications in preparation for a pandemic.</td>
<td>33.30%</td>
<td>0.00%</td>
</tr>
<tr>
<td>10) The current stockpile of food in our homes, agencies and communities is sufficient for a pandemic.</td>
<td>12.50%</td>
<td>18.80%</td>
</tr>
<tr>
<td>11) During a pandemic, I would look to my local health department website for the most reliable information.</td>
<td>68.80%</td>
<td>0.00%</td>
</tr>
<tr>
<td>12) I could accept, support and perform actions to provide services / resources for the greater good, knowing that others may not receive the same services.</td>
<td>81.30%</td>
<td>12.50%</td>
</tr>
<tr>
<td>13) The NYSDOH or your county DOH should supply each household a basic emergency kit, with guidelines on pandemic flu, including facemasks, free of charge.</td>
<td>37.50%</td>
<td>37.50%</td>
</tr>
<tr>
<td>14) The NYSDOH or your county DOH should supply each household a basic emergency kit, with guidelines on pandemic flu, including facemasks, and charge residents for the kit, based on the ability to pay</td>
<td>87.50%</td>
<td>0.00%</td>
</tr>
</tbody>
</table>
Appendix E: Focus Group Notes

Albany area: Twelve participants and five facilitators/note-takers observing:

**What brought you to this meeting?**
- A friend told me.
- I’m a nurse/service provider and wanted to know more to help my clients.
- I wanted to represent the youth voice.
- I’m elderly and wanted to know more information.
- I am involved at an independent living center and learned about it there.
- I am disabled and need to be prepared for myself.
- Firefighters/EMT told me about it.
- I am a parent, grandparent and involved in disability groups.

**Best part of the meeting?**
- The creativity and different perspectives from all involved.
- Talking in small groups.
- Talking with each other and sharing different ideas.
- Learning to trust the government.
- Being involved in local planning.
- Ability to openly share our concerns about having too much information and not knowing what we can trust and what is accurate.

**What could be improved?**
- I didn’t like the pollable ballot—I wanted to rank all of the issues by importance to those of us in the meeting rather than vote on them.
- Would have liked to provide input on where resources are focused.
- Want the pharmaceutical companies and the government to focus on developing systems now to help people gain immunity now and not wait till we are faced with a pandemic—pro-active rather than a reactive approach.
- Put money with the people and do more of these community listenings – people know what’s important in their own state and community.
- Look to the emergency management people, EMTs and firefighters, they are trusted in each community!
- Educate more at a local community level soon and cross many cultural barriers.

Cortland County: No additional notes
**Chautauqua County:** Two participants

*Best part of the meeting?*
- Presenters
- Presentations
- Amount of participation by people
- Small groups worked good.
- Good information to take back for emergency management plan and communication
- Linkages with other groups, like Home Health Association

*What could be improved?*
- Too many nurses in one group. Passions got very deep.
- I thought I would learn how I could help my community. This was clearly set up to help the state, based on the materials that were sent out in advance.
- Black on blue is awful for sight-impaired people.

**Nassau County:** No details on number of participants

*Best part of the meeting?*
- Had ample time to express myself.
- Got out earlier than planned.

*What could be improved?*
- Did not get much information at this meeting.
- Need to know who to call at Nassau County DOH if I have follow-up questions.
- Contact information for local DOH staff should have been prominently displayed.
- Could have used more explanation of the handout materials and more time to read and digest all the materials provided.
- There were too many elderly at the meeting. A broader cross-section of Nassau County should have been here.
- Wanted to hear more about the vaccine prioritization effort.
- Needed more discussion topics to address in the small groups.
- We did not return to the general discussion that opened the meeting. I would’ve been good to have a general discussion at the end of the meeting just to wrap things up.
- The unique poll questions were not provided in Spanish.
Appendix F: Facilitator Debrief
Albany-area

General Description of participants at your table:

- Engaged interested- three men, three woman, one disabled, one married couple, one service/care provider one MD and one nurse.
- Seven people at table, one with physical disability, one with mental health issues, a minority (African American), and a service provider (advocate for persons with mental retardation).
- Seven people (average age was 45), varied ethnic backgrounds, Latino, African American, Hispanic, homeless white person, person with mental health issues, some who are employed and others unemployed.
- Seven highly educated people from varied backgrounds, Hispanic, Asian African American, Mental health issues; English not some of their first language.

Overall: How did you feel the format worked for your group?

- Intro was too formal for this group.
- SME white male in a suit did not work (in writer’s opinion). Too formal, too academic.
- Q&A was too formalistic; some questions needed more information and there remained a concern by some people in attendance about how poor people can stockpile food and supplies without state and federal support.
- Topic and educational pieces were engaging.
- More trust in government was stated and this community level effort is important to begin to build those ties.
- Some confusion by F/NT and participants on the tabletop discussion topics. These should be shared with participants and written in plain English as well as covered in the pre-meeting training.
- Difficult to hear in a room with high ceilings and many people in close proximity—having small break out rooms would have been preferable.
- Everyone was engaged and respectful of others for the most part.
- Good physical layout.
- Question on “Trust” was lively! Many felt this was one of the most important parts of the discussion. Hoping the state will continue to engage the public in this type of training and community planning/engagement efforts.
- Put together a checklist on supplies and nutritional information for communities to have and use when stockpiling food and gear.
- Creativity of the people in the room was the biggest highlight of the day.
- People worked very hard all day, very positive group, focused on solutions to problems raised and suggestions.
• Format worked in gathering information on the topics listed.
• Majority of people in the room were interested in promoting suggestions that they would feel comfortable working with.
• Prioritization of vaccination, medical supplies and antivirals are of concern to many.
• People are concerned about information not being shared and medication being withheld from minority and underprivileged populations.

What worked best?

• Small group discussions.
• Getting diverse group of people together.
• Allowing time for deep discussion and not having experts with answers at each table.
• Letting the groups work at their own pace.
• Having good food and enough of it!
• People were interested in the topic.
• Having people spread out in small groups.
• Discussion topics helped elicit more information.
• Asking for suggestions and ideas and then letting people give you priorities.

What worked least well?

• Amount of time too much small group time people got tired even though they were very interested in the topic—long day.
• Structure of the question needed more flow.
• Difficult to hear in such a large room.
• Lunch was served too late (12:15 pm).
• Better screening prior to meting so people with mental health issues don’t disrupt the meeting.
• Too many pollables for people to complete—loss of interest at end of day.
• Do polling sooner when people have more interest. Sidebar conversations in small groups were bothersome to some people.
• More education and materials for the participants to take home.
• Live education by a speaker who then answered the questions would have been better.

Did the meeting reach its objectives?

• Yes—within the limitations of the people who were in attendance.
• Some people were uncertain that this process would make a real difference as they feel during a public health emergency the state and local public health officials will do what they need to not considering this information.
• Discussion was worth the effort and many people shared deeply.
What part did you feel least comfortable facilitating?

- Challenged by the Q&A section when not all questions were answered fully or as I would have liked to have seen them responded to.
- Some in audience were aggressive—this bothered me.
- Some people may not have been as vocal when they learned I was a government public health employee. I had some difficulty with following the discussion points and keeping people engaged.

Lessons learned

- Too formal a discussion for most involved, most want informal discussions.
- Have a panel discussion rather than one white man in a suit giving generic replies.
- More trust building exercises and training throughout the state are needed.
- Much more education in plain English and hands-on work to build relationships.
- Shorter time for small group discussions.
- More outreach to build trust in communities.
- Use churches, synagogues, community centers, mosques, VA centers as resources.
- Keep the relationships in place with people once established.

Cortland County

General description of people at your table

- Speech and writing difficulties, volunteer workers, visually impaired, college students, diverse group, very involved in discussion, social service workers.

Overall: How did you feel that the format worked for your group?

- Small group worked very well.
- Excellent guidance provided to stimulate discussion; participants very interactive; all respectful of the ground rules.
- Overwhelming. Questions difficult.
- They moved quickly through the questions but had great responses. Didn’t need as much time as allowed.
- Excellent group raised a lot of ideas.

Specifically: What worked best

- Participants most engaged in the issue of stockpiling medication.
- Polling.
- Giving participants time to give their opinion and having the facilitator make sure everyone was heard.
• The expert Dr. Maliha because he gave great information on specifics not often covered in communication with the public.
• Facilitator prompts to each participant encouraged all to share ideas, suggestions.
• Participants enjoyed the video and were engaged in the reading of the scenario.

**Specifically: What worked least well?**

• Participants lost interest in the issue of ventilators.
• Participants had little interest in the issue of childcare until it was mentioned that seniors will be asked to fill in to care for children.
• Too long, too hard to hear.
• Took too long during polling.
• The participants never lost interest.
• Group lost interest toward the end of the questions.

**Do you think this meeting achieved our goal?**

• Got input on issues the state was interested in.
• The group did learn.
• Conducted the meeting in a trust-building manner
• Formed a great community bond

**What part(s) did you feel least comfortable facilitating?**

• Ventilator issue because of lack of interest.
• Some of the questions because I lacked understanding as to why they were asked.

**Lessons Learned**

• By 2:00 pm everyone was ready to go and was given enough opportunity to express their concerns and opinions.
• The groups should be planned rather than sit wherever. Grouped by common communities or focus questions to them or make sure that groups are representative of communities.
Chautauqua County

Lessons Learned

- Black type on dark blue paper is the worst thing for visually impaired people.
- The meeting room with multiple groups, hard for participants who were to some degree hard of hearing.
- Can’t combine facilitator and note-taker. Need two people.
- Before leaving we should empower people to do something.
- Needed more recruitment for community members.
- Discussion topics need to be shared with the groups (we actually did this in Chautauqua County).
- Recruitment should be based on roles, rather than on individuals’ personal concerns.

Nassau County

General description of participants at your table

- Concerned about people who cannot read or understand the message being able to follow directions to care for their family.
- Educated. RN’s, Attorney, Retirees, former educators, former Health care workers, Non-profit workers, former teachers.

Overall: How did you feel the format worked for your group?

- The format was great. Everyone talked and developed good ideas and respected each other.
- Significant discussion.
- Great group discussion.
- Very well—but summary could have been given by each group after each question.

Specifically: What worked best?

- Facilitator questions were thought-provoking.
- Small group discussion generated tremendous thought and participation.
- The questions that were more family/home/work-based got the most response since they could relate to it.
**Specifically: What worked the least well?**

- If a side bar discussion took place, participants lost interest because it did not pertain to them.
- Group of participants not really the target audience.
- Participants completed the general survey together without a real ability to participate or have questions clearly understood.
- They seemed interested throughout.

**Do you think that this meeting achieved our goals?**

- To obtain public input on the state’s pandemic planning.
- Yes, very much so—found out that they really didn’t trust public health info.
- Created a meaningful environment that will enhance the opportunity of community members to discuss a critical health issues.

**What parts did you feel the least comfortable facilitating?**

- Not enough time to summarize points and document thoughtfully (may have lost a few group suggestions).

**Lessons Learned**

- The small environment and the limited number of participants fostered a more trusting environment and allowed participants to open.
- More filtering to get people with special needs to the table.
- Follow outline and summarize for all to hear other tables’ views after each question.
- It appeared that some group facilitators drove the conversation toward their own issue/knowledge even though they should remain neutral—raised issues that were outside the scope.