

# **Pandemic Flu Citizen Engagement Report on Values Meetings**

Submitted to the Mid-America Regional Council

December 16, 2006

By One KC Voice and Consensus

Health and emergency agencies across the region are preparing today to respond to an expected influenza pandemic. They are listening to influenza experts worldwide, including the World Health Organization, who warn of the inevitable emergence of a new, severe strain of the influenza virus against which we have no natural immunity.

Pandemic flu occurs three to four times per century, can take place in any season, and may come in “waves” of flu activity that could be separated by months. Experts predict an infection rate of 25 percent to 50 percent of the U.S. population. All age groups are at risk, with a mortality rate determined by the severity of the flu strain.

Three pandemics swept the globe in the last century: “Spanish influenza” in 1918, “Asian influenza” in 1957, and “Hong Kong influenza” in 1968. The 1918 pandemic, one of the deadliest disease events in human history, killed an estimated 40-50 million persons worldwide. Experts predict that a moderately severe flu pandemic could kill more than a half a million Americans, hospitalize more than two million, and cost the U.S. economy \$70 to \$160 billion. Experts expect pandemic influenza to cause substantial economic and social disruptions.

The pandemics of the 1900s circled the globe in six to nine months, even when most international travel was by ship. We know that, even with border closures and travel restrictions, the pandemic flu may be delayed but not stopped. Communities throughout the U.S. must, therefore, be prepared to take action to protect themselves.

A successful response to a pandemic flu outbreak in the metro Kansas City region depends on citizens playing an active and predictable role in the region’s response. Citizens, however, may not act as public health officials predict and may instead act on a set of public values, which are not always clear to health officials. The Pandemic Flu Citizen Engagement proposes to bring planning for a pandemic flu response into sync with public values, so that public health directions and actions will be understood, supported, and followed by the public.

The primary issue affecting diverse citizens in the five-county region is that public health plans sometimes ask the public to take actions that are simply unacceptable. Given human nature and public values, then, it requires conversations with citizens and public health officials to determine how citizens can best be expected to help meet public health goals.

Metro Kansas City has an historic opportunity, supported by public health officials, to assure that our citizens are not put at risk by public health plans that do not fit with

citizens' legitimate, real-world concerns. It is an opportunity to save lives and build confidence in government response to a large-scale crisis.

The Pandemic Flu Citizen Engagement is guided by a steering committee of 14 persons, and includes the counties of Wyandotte in Kansas and Eastern Jackson and Clay in Missouri, along with the City of Independence. The steering committee is convened by Dan Blom of One KC Voice and Jennifer Wilding of Kansas City Consensus. Its citizen members are Carol Cobb, Elaine Lenz, Steve Pew, Wayne Vaught, Lois McDonald and David Smith. Its health department members are Gay Hall (Wyandotte), Jodee Fredrick and Nola Martz (Clay), Josh Walsh and Kate Donaldson (Independence) and Nicole Schlaefli and Rhonda Charboneau (Jackson). Marlene Nagel represents the Mid-America Regional Council and Mike Chamberlain represents the American Academy of Family Physicians.

### **Results from the values meetings**

In November, 2006, the project conducted 13 meetings designed to elicit the community's values. The meetings were held in each of the four communities involved in the project. They ranged in size from two residents to some 95 senior citizens. Most meetings included 6-10 participants. Each meeting provided valuable information about the questions that citizens would need to have answered and the actions that they would take to prepare for and respond to a pandemic flu crisis.

The meeting sponsors were members of the One KC Voice Citizen Engagement Network. Sponsors included:

- Progress Independence, meetings held at Tri-City Ministries, Fairmount Community Center, and Palmer Senior Citizen Center.
- Northland Neighborhoods
- Rosedale Development Association
- Livable Neighborhoods
- League of Women Voters of Kansas City/Jackson, Clay and Platte Counties
- Bonner Springs City Library
- City of Blue Springs
- Mount Zion Baptist Church
- Kansas City, Kansas, Public Library
- Lee's Summit Chamber of Commerce
- Family Partnership

### **Summary of findings to date**

The Pandemic Flu Citizen Engagement has produced many findings. What follows are a summary of major themes.

**Toughing it out versus seeking medical treatment.** When it came to caring for elderly or young family members, participants would go to great lengths to see to their needs. If their child's dorm was under quarantine and the child was not sick, parents said they would bring the child home. If there was a ban on travel, one citizen said he would still drive to get his mother in another town. If a loved one was sick, caregivers would get that person to the hospital if the symptoms warranted. When it came to taking care of themselves, however, many people, especially those who lived alone, said that they would tough it out without seeking medical care or help. Their major concern was that they not make their own caregiver sick. While some seemed to understand that the pandemic flu could be fatal, many seemed to equate it to the seasonal flu and wondered what a hospital could do for them that they couldn't do for themselves.

**Optimists vs. pessimists.** The meetings saw a clear split between people whose outlooks may be termed optimistic and those who are pessimistic. The optimists expected that some agency or government entity would deliver food to the sick, that they would continue to receive some pay from their employers, and that creditors wouldn't seek payment during an emergency. The pessimists expected that all systems would break down and no assistance would be available, that resources would be directed towards retrieving the dead rather than helping the living, and that they would receive no payment from their employers. Even pessimists, though, assumed that there would be a grace period on bill payment, and even optimists said they understood the need for individuals to stockpile food and practice good hygiene in order to be responsible for themselves.

**Knowledge about pandemic flu is limited.** Surveys are being tabulated and the final results will be available early in 2007. A quick review of the results show that the public's understanding of the pandemic flu is not extensive. In some cases, we can expect a lack of knowledge to be combined with a lack of trust in the government. For example, at one meeting, some participants did not understand why, if the pandemic flu was coming, they would not be able to get a flu shot to protect against it. They did not understand how a flu vaccine is manufactured and that one probably wouldn't be available for a particular type of flu until six months after that strain appeared. In communities where residents tend to distrust the government, the potential exists for people to think that others have access to a vaccine and they don't. There is also the potential for people to avoid taking precautions because they believe a vaccine will be available.

**People are, generally, comfortable seeking out information.** Citizens were asked where they would go for information. At the beginning of a crisis, when they were working to prepare, they said they would watch or read media reports. For more detailed information, people cited several organizations whose websites they would visit: the Centers for Disease Control, the World Health Organization, or their local public health department. Most participants said they would seek out information, although one group said they expected that "they" would provide information to them. "They" seemed to mean the government. Members of the disabilities community said they would turn to their physicians immediately for information and advice.

**Needs to establish credibility and urgency will require different kinds of communication.** When the pandemic flu begins to hit Kansas City, and there is a sense of urgency around communication, citizens said they would favor an integrated strategy involving both medical experts and respected leaders from their community. While this was particularly true in communities of color, it was echoed in predominantly white communities, as well. People said that they wanted the medical and health information from an expert, not a politician. They would take that information more seriously, though, if the expert was introduced by a respected leader from that community. Examples of respected leaders were Sunday school teachers, business owners, and some elected officials. Doing this would, in the words of one participant, help break through denial and distrust by showing that it wasn't just government folks talking again and that nobody would gain financially by what they were being asked to do.

**Neighborhood and church leaders are a potential resource.** In any community, there are people who, by position or by personality, have the desire to help others. During our meetings, people who were in leadership positions in their neighborhoods and their churches were likely to ask for information about what they could do to help people prepare and to assist in the case of a pandemic flu emergency. Our sense is that they can be a valuable resource for local health departments if health departments choose to utilize them.

**In general, people expect to care for one another.** One overriding theme was that people expect that they will be involved in caring for others during a pandemic flu emergency and its aftermath. They expect to take food to the sick, call neighbors and relatives to check on them, and assist where needed. After the emergency, they would expect that those who had lost loved ones would turn to each other and to their churches to get through the grieving process. It is important to note that the people who attended these meetings didn't necessarily view themselves as typical of the entire population. They expect that many people will be in denial, and that some will go so far as to engage in theft and looting as they struggle to survive.

### **Results from participant survey**

Participants were asked to complete a survey that tested their knowledge about pandemic influenza, their preparation and hygiene practices, and actions they might take in the case of a pandemic.

None of the knowledge questions received higher than 67 percent correct response, and average for all questions was 48 percent correct. The highest percentages of correct responses were to questions about the mortality rate, how the flu is transmitted, whether existing vaccines would work against a new flu strain, and whether bird and pandemic influenza were the same things. Two of the eight questions got a very low correct response. Only about a quarter of respondents knew that it would take about six months for a vaccine to be available and that influenza pandemics occur about every 25-30 years.

<b>Knowledge Questions: Combined Totals</b>			
<i>The correct response is shaded. Total numbers differ because some individuals didn't answer every question.</i>	<b>True</b>	<b>False</b>	<b>Don't Know</b>
Pandemic flu affects mainly the elderly and very young.	34 27%	<b>59</b> <b>47%</b>	32 26%
Existing vaccines would not work against a new strain of the flu.	<b>70</b> <b>56%</b>	16 13%	39 31%
Pandemic flu would strike during the winter.	27 29%	<b>45</b> <b>48%</b>	21 23%
It would take about six months for a vaccine to be available.	<b>31</b> <b>27%</b>	17 14%	70 59%
You can only get the flu from breathing germs.	13 11%	<b>70</b> <b>58%</b>	37 31%
Bird flu and pandemic influenza are the same thing.	12 10%	<b>68</b> <b>56%</b>	41 34%
A flu pandemic would kill about the same number of people that the regular (seasonal) flu does every winter.	6 5%	<b>80</b> <b>67%</b>	33 28%
Influenza pandemics occur about every 25-30 years.	<b>30</b> <b>25%</b>	31 26%	58 49%

The great majority of participants – 92 percent – wash their hands at least five times a day. The lowest score was for stockpiling food, water and supplies – 56 percent – but even that was above half of all survey takers.

<b>Preparation / Hygiene Questions: Combined Total</b>		
<i>Total numbers differ because some individuals didn't answer every question.</i>	<b>YES</b>	<b>NO</b>
I get a flu shot almost every year.	95 71%	38 29%
I keep a stockpile of food, water and supplies in case of an emergency.	69 56%	54 44%
I wash my hands at least five times a day.	121 92%	11 8%

The great majority of participants – 88 and 87 percent, respectively – would avoid crowds and stay home as long as they felt sick. Fewer said that they would wear a medical mask, although the 53 percent response was above half of all participants. That question received the highest – 25 percent – “don't know” response. Sixty percent of participants said that could work at home if their workplace was closed. When asked where they would go for information about what to do after pandemic flu hit metro Kansas City, most participants – 51 percent - said they would contact their physicians.

<b>Action Questions: Combined Totals</b>			
<i>If an influenza pandemic hit...</i>	YES	NO	Don't Know
I would wear a medical mask to avoid germs.	61 53%	26 22%	29 25%
I would stay at home for as long as I felt sick.	92 87%	7 7%	7 7%
I would go to work no matter what, even if I was sick.	8 7%	104 86%	9 7%
I could work at home if my workplace was closed.	60 60%	35 35%	14 14%
I would avoid crowds until the pandemic flu was gone.	109 88%	7 6%	8 6%
<i>If the pandemic flu hit and I wanted information about what to do, I would...</i>			
...contact my physician for information.	41 51%		
...seek information from my local public health department.	27 33%		
...count on the media to provide information.	14 17%		
...go to a trusted friend for information.	0 0%		

### **Questions raised by participants**

During the meetings, citizens are asked to offer questions or concerns that they would have in four situations: 1. the pandemic flu has just come to the U.S., but only a few cases have appeared in Kansas City; 2. the pandemic flu has hit Kansas City hard, and they are not yet sick; 3. they have contracted the pandemic flu; and 4. a vaccine is available.

A major responsibility of local health departments will be to provide accurate, useful information to citizens. The questions and concerns can guide health departments in the kind of information they provide.

### **Preparations involving various groups**

- What are the steps that neighborhood and church leaders should take to prepare for the pandemic flu and to protect their communities once the flu hits?
- Do schools, colleges and universities have pandemic flu plans? How will they educate students on how to avoid spreading the flu?
- What plans do utility companies have to provide water and keep lights and heat on?
- What role would the safety-net clinics have in preparing for and treating a pandemic?

- What is my city doing now to get emergency supplies in place?
- At what point would a state of emergency be declared? What happens then?
- If there are no shelters for people to go to if hospitals are overwhelmed, what can we do now to get shelters in place?
- Will there be facilities to handle cadavers? If someone in my household dies, what will I do with the body?

### **Supplies**

- What do I need to have in my house in order to be self-sufficient?
- What kind of mask should I buy?
- What types of flu would help keep you from getting the flu?
- What foods would both keep for a long period of time and provide high amounts of nutrients?
- How much food and water should I stockpile?
- Insurance allows no more than a 30-day supply of prescription medications. How can we assure we have enough medicine on hand for pre-existing conditions?
- Will there be a way to get food and water to sick people?

### **Isolation and risk**

- How do I keep from bringing the flu home?
- At what point would I need to keep my children home from school?
- Will the government barricade areas in time to isolate sick individuals?
- How long will I need to stay at home?
- What do you do with infected trash that is set out for pick-up?

### **Caring for the sick**

- If someone in my house is sick, do I need to report it to somebody?
- What are the best techniques for caregivers to use to avoid spreading the flu?
- Are pandemic flu symptoms different than for the seasonal flu? How would we know if it was the pandemic flu or a cold?
- How might the symptoms show up differently in people with different pre-existing conditions?
- Can the seasonal flu shot protect you against the pandemic flu?
- At what point do I need to take a sick person to the hospital?
- What could a hospital do for a sick person that I can't do at home?
- Are there over-the-counter medicines that would be helpful?

### **Economic impact**

- Will employers be able to force employees to come to work? What if people are afraid to go to the job site?
- If a state of emergency is declared, will there be some type of grace period for paying bills?
- What are the obligations of employers in a pandemic flu crisis? Would they have to pay for unused sick and vacation time, or pay something to sick employees?
- After six months, we'll be out of everything. Once we're in recovery, how will store shelves be restocked?

### **Vaccinations**

- How soon does the vaccine take effect after injection?
- Who will decide who gets the flu vaccine, if not enough is available for everyone?
- Who gets the vaccine first? Will it be distributed in an unbiased manner?
- Would doctors as well as hospitals have the vaccine, as is the case with seasonal flu?
- Where will distribution centers be located? Will they be accessible to people who don't have cars or gasoline?

One KC Voice and Consensus appreciate the opportunity to conduct these values meetings in an effort to engage citizens in preparing for the pandemic flu. We expect that what we have learned can help guide health departments and others as they consider how best to inform and involve citizens.