What should we do about the flu?

A citizen conversation about our policies and preparations for the next Influenza pandemic

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Agenda for the day:

- 8:30 Registration
- 9:00 Opening plenary Pandemic flu and the federal decision-making process (*large group*)
- 10:30 Break
- 10:45 Session 1 What values should guide our decision-making? (small groups)
- 12:00 Lunch, with Q&A for the experts
- 1:00 Session 2 How should we allocate vaccines during a flu pandemic? *(small groups)*
- 2:30 Break
- 2:45 Session 3 How should we help prevent or contain a pandemic? (small groups)
- 4:15 Final plenary
- 5:00 Adjourn

Introduction

Why is this issue important?

Influenza is one of the most common diseases we know. In a normal year, it causes tens of thousands of deaths in the United States. But every so often, the virus changes form, touching off a worldwide outbreak that can claim millions of lives – because it crosses international borders, it is not just an epidemic, but a pandemic. This is what happened in 1918, 1957, and 1968.

Scientists studying the virus say that it is only a matter of time before another pandemic occurs. In a normal year, people over the age of 65 are the ones most likely to die from the flu, but pandemics often target different sets of people: for example, the "Spanish flu" of 1918, which claimed 50 million lives worldwide, was most deadly to healthy people between the ages of 18 and 45.

Flu vaccines must be redeveloped every year, based on the form the virus has taken that year. Because pandemics grow very quickly after the virus has mutated, there will be little time to develop new vaccines. As a result, it is likely that there will be little or no vaccine during the beginning stages of the next pandemic.

How will this event make a difference?

Public health officials want to know what you think about this challenge. Officials at the U.S. Department of Health and Human Services and the Centers for Disease Control and Prevention have worked with a variety of nonprofit organizations to gather citizen input about the possibility of an influenza pandemic. This forum in Atlanta is a focal point for this citizen involvement effort. As citizen advisors, you and other Georgians have the chance to give vital input on the options facing the U.S. for the use of flu vaccine.

"We are very interested in knowing what the public thinks about these issues," says Dr. Alan Hinman, a member of the National Vaccine Advisory Committee. "The conclusions reached in Atlanta will definitely have an impact on the national pandemic plan being prepared by the Department of Health and Human Services." Your input will also have an impact on the State of Georgia's own pandemic response plan.

In addition, you will have the chance to talk about what plans might be made locally to prepare for the possibility of a pandemic. State and local health officials, medical professionals, academics, and other influential decision-makers will all be taking part in the forum, and many others will be reading the report that emerges from the event.

What do you need to know?

There are minor changes in the flu virus all the time – these are known as "drift." Sometimes a major change occurs, a "shift" which triggers a pandemic.

Seasonal Influenza

There is an average of 36,000 flu deaths in a normal year – 90% of those among people over age 65. Influenza vaccines are 70-90% effective in preventing illness

among healthy individuals less than 65, but less effective for the elderly (30-40%), though it does still reduce hospitalizations and deaths. Flu vaccines are not available for infants younger than six months.

- When a vaccine supply was cut in half in October 2004, CDC came up with a priority list:
 - 1. Infants between the ages of 6 months and 23 months
 - 2. Pregnant women
 - 3. Residents of nursing homes and long-term care facilities
 - 4. Healthcare workers with direct patient care
 - 5. Persons 65 years and older
 - 6. Household contacts and out-of-home contacts with those under 6 months.
- Vaccines need 3-4 weeks to take effect before you are exposed to the virus.
- A typical flu season in a normal year lasts 10-11 weeks.
- Only 1 per 100,000 doses of the flu vaccine can have neurological side effects. Some recipients get severe reactions to egg protein in vaccine, and others get lowgrade fever. Only 20-30% of those vaccinated exhibit flu-like symptoms (fever, cough), but it is not the actual flu.

Pandemic Influenza

- It is estimated that 25-30% of the population will become ill (20-30% of working age) in the first major wave of a pandemic. Rates of hospitalizations and deaths depend on age and risk group and the nature of the virus.
- The CDC estimates that in Georgia alone, a pandemic would kill 13,000 people and hospitalize over 80,000.
- > Pandemics have often lasted 8 weeks and can include more than one wave.
- We should assume that imported vaccine will not be available during a pandemic event, that two doses may be needed for protection, and that the first vaccine will be available in 4-8 months.
- There are "antiviral" drugs that may help prevent and treat influenza. However, the global production of antiviral drugs is limited.
- If the U.S. and other countries dramatically increased their orders for flu vaccines and antivirals, then the pharmaceutical companies would build more production facilities – making them better able to make massive quantities of the drugs in a crisis. However, this would be an expensive proposition.

Session 1 – What values should guide our decision-making?

(75 minutes)

Doctors, scientists, and public officials all have important roles to play when it comes to making decisions about a flu pandemic. But those policies and procedures should reflect what ordinary citizens think, and the value judgments they make, about these issues.

This session will give us the chance to talk about why these issues matter to us, and what values we should uphold as we plan for the possibility of a pandemic. It will lay the foundation for the rest of the sessions, and set the tone for open, thoughtful discussion.

Part 1 – Setting the ground rules (5-10 minutes)

Setting a few ground rules will help the discussion run more smoothly. Below is a list of examples – do these ground rules seem helpful? Are there others you want to add?

- Listen with respect.
- Each person gets a chance to talk.
- One person talks at a time. Don't cut people off.
- Speak for yourself, and not as the representative of any group.
- If someone says something that bothers you, say so, and say why.
- It's OK to disagree, but personal attacks are not allowed.
- Help the facilitator keep things on track.
- Outside of the group we will not quote what is said in the group.

Part 2 – Experiences with these issues (20-25 minutes)

Tips for the facilitator (and the group)

- Welcome everyone and explain your role.
- Divide the session into four parts, and use the time suggested for each as a guide.
- On the first question in Part 2, go around the circle and make sure everyone has a chance to answer.
- Take the rest of the Part 2 questions in whatever order you wish – you don't have to cover them all!
- 1. Introduce yourself. What brought you to this forum? Why are these issues important to you?
- 2. In two or threes at the table discuss the question, "Have you ever lived through a public health emergency or some other kind of natural disaster? What do you remember most about that experience?"
- 3. What do you think are the most pressing challenges when it comes to dealing with the possibility of a flu pandemic?
- 4. What do you think are our greatest strengths, in our public health system and in our community, for dealing with these challenges?
- 5. In what ways can citizens, scientists, and public officials better communicate with each other, and work together on these issues?

Part 3 – What values should we uphold? An ethics exercise (35-40 minutes)

The decisions we make about how to prepare for a pandemic, and particularly about thorny issues like how to allocate vaccines, should be based on good science and carefully considered values.

The following scenarios will give you a sense of how difficult these decisions can be. As you read and discuss each scenario, take a look at the boxed "List of values."

Scenario 1 – Five children are playing on a trolley track as the train approaches. If the trolley car is diverted to a spur, their lives will be saved, but one child is playing on the spur. The driver has a heart attack. You would be able to divert the trolley.

Scenario 2 – You are a surgeon with five patients who need five organs. You could kill one healthy person and save all five.

Scenario 3 – You are a doctor with 100

List of values

Here are some possible values you may want to consider as you think about the scenarios:

- We should strive to do the greatest good for the greatest number of people
- We should try to ensure fairness and justice
- We should value children and young people above older people
- We should preserve public safety and the normal functioning of society
- Whatever we do, we should try not to do harm.

patients. Fifty of these patients (you know who they are) need two doses of vaccine to be protected from a deadly disease. One dose does not help them. Fifty of these patients need one dose to survive. You have 50 doses of vaccine, and you can't get more. Except for their dosage needs they are the same in every way.

6. What would you do in each of these situations? Which values would you try to uphold?

Part 4 – Wrapping up the session (10-15 minutes)

- 7. [For the recorder:] What were some of the main themes from the discussion?
- 8. [For the group:] Were there any other themes that should be listed, or any other changes made, in the group record?
- 9. What did you like best about how the group process worked? What would you add or change?

Session 2 – How should we allocate vaccines during a flu pandemic? *(90 minutes)*

Deciding who should get the influenza vaccine in a pandemic, when tensions are high and supplies are limited, is likely to be difficult and controversial. Before a pandemic hits, public officials need to have a clear sense of what citizens want them to do.

This session will focus on some of the possible goals for a pandemic vaccination policy. It will help us see how the values discussed in Session 1 could be applied to the decision about how to allocate vaccines. For more on the assumptions that went into developing this list of goals, see p. 10.

Part 1 – Potential goals for a vaccine policy (45-60 minutes)

Tips for the facilitator (and the group)

- Remember to use the ground rules the group set in the first session.
- Divide the session into two parts, and use the time suggested for each as a guide.
- Ask for volunteers to read each goal aloud, and then ask the discussion questions that follow the goals.

The list below is intended to help the group consider a range of views about how we might

allocate vaccines during a pandemic. The goals could be used to create a "priority list" for immunizing people in the event of an epidemic.

This list is not comprehensive; it is meant to represent the opinions that are commonly heard when discussing these issues. As the group discusses these goals, you may find yourself agreeing with more than one of them. Feel free to combine goals, and to describe others that are not on this list.

Goal 1 – Save those who are most at risk.

The question of who is most at risk cannot be determined conclusively until after the pandemic begins. However, based on past experience, there are several likely implications of this goal.

- School-age children might *not* be near the top of the priority list, because they may be less likely to die of the disease.
- Children aged six months to two years would be at or near the top of the priority list.
- Senior citizens, pregnant women, and people with other health conditions would be at or near the top of the priority list.

Goal 2 – Put children and young people first.

Possible implications of this goal:

• Children and teenagers would be at or near the top of the priority list, regardless of their level of risk.

Goal 3 – Limit the larger effects on society.

There are some vastly different ways to implement this goal, depending on your sense of what is good for society:

- Police officers, firefighters, and other emergency services personnel would be at or near the top of the priority list, OR
- The military would be at or near the top of the priority list, OR
- Health care workers would be at or near the top of the priority list, OR
- Public officials and other decision makers would be at or near the top of the list.
- Vaccines would be shared with countries where treatment could slow the spread of the disease.

Goal 4 – Use a lottery system.

Possible implications of this goal:

- Vaccines would be distributed randomly.
- It would also be possible to make the lottery 'transferable' people who won the right to a vaccination could choose to pass it on to another family member instead.

Goal 5 – Use the principle of 'first come, first served.'

Possible implications of this goal:

- Vaccines would be given out to anyone who asks for them, until supplies run out.
- Vaccines would also be available through private doctors or through company health plans.

Discussion questions on the goals:

- 1. How have the values discussed in Session 1 shaped what you think?
- 2. What other goals would you add? What is missing?
- 3. Which goals do you support? Why?
- 4. When you compare the goals, what are the trade-offs between them?
- 5. Can you think of situations where the trade-offs would be particularly troubling? How should we handle those situations?

Part 2 – Ranking the goals and wrapping up the session (30-45 minutes)

- 6. Voting process for ranking the goals:
 - Each person gets three colored stickers.
 - Each person puts stickers on the newsprint next to the ideas you like best. You can use all three votes on one idea, or you can spread them around.
 - Count the stickers.
- 7. What do you think of the results of the sticker exercise? The rankings may not mirror your own preferences perfectly, but are they acceptable to you?
- 8. Who is not represented at this table? What might they say about these choices? Are these goals biased by the make up of this group?
- 9. Aside from the rankings, were there any other themes or action ideas that should be listed in the group record.
- 10. What did you like best about how the group process worked? What would you add or change?

Session 3 – How should we help prevent or contain a pandemic?

(90 minutes)

The question of how we should allocate vaccines is only one of the decisions that must be made. There are many ways to prevent or contain a flu pandemic, and many of them can be implemented at the local level. Everyone has a role to play: citizens, health care providers, scientists, nonprofit organizations, businesses, and public officials. This

session will allow you to discuss some of these approaches and decide how you might put them into action.

Part 1 – Considering different areas of work (45-55 minutes)

The list below is intended to help you consider a range of ideas about how to move forward. You may find yourself agreeing with more than one approach. Some approaches that are important to you may not be on the list – feel free to combine approaches or add new ones.

Tips for the facilitator (and the group)

- Time is short divide the session into two parts, and use the time suggested for each as a guide.
- Ask for volunteers to read the title and paragraph for each area of work aloud, and then use the discussion questions that follow.
- The group does *not* have to rank the areas of work.

Area of work 1 – Ensure that we have adequate capacity to respond to the disease.

Instead of focusing on how to distribute limited quantities of vaccines, we should be finding ways of increasing the overall supply. We should place larger orders for vaccines and for antiviral drugs. Even if the mutation of the virus forces scientists to develop new vaccines during the pandemic, the greater capacity of the pharmaceutical companies will make it easier for them to produce larger amounts in a hurry. We also should ensure that we can care for large numbers of patients in a pandemic – we should have contingency plans to provide more beds in case hospitals become filled to capacity. Finally, we should think about how a pandemic might affect public safety and the economy, and develop plans that keep communities, businesses, and organizations running when large numbers of people cannot work.

Possible action items under this approach:

- Stockpiling vaccines.
- Stockpiling antiviral drugs.
- Creating emergency plans for increasing hospital capacity.
- Preparing information for people who will be caring for patients at home.
- Creating support networks for people who will be caring for patients at home.
- Developing crisis plans for all major organizations governments, businesses, etc.
- Working with other countries to ensure a coordinated response to pandemic flu.

Area of work 2 – Find other ways to arrest the spread of the disease.

There are many ways to slow or halt the spread of a pandemic. The most basic is good hygiene: encouraging people to wash their hands and prevent the spread of germs. Day care centers often have convenient handwashing stations near their entrances, and signs reminding parents to use them; this kind of practice could be employed in other places. Businesses and other organizations could have emergency sick day policies to be put in place in case of a pandemic. It will be important for health agencies to be able to track and study the pandemic, so people need information on how to identify symptoms and report possible cases of the disease. Finally, public health officials must be prepared to close buildings and organizations in order to limit the spread of the disease.

Possible action items under this approach:

- Good personal hygiene.
- Signs and other ways to communicate the importance of good hygiene, and organizational policies that require it.
- Handwashing stations in locations where disease is likely to be spread.
- Local health hotlines or other systems that allow people to report cases of the disease.
- Plans for the closure of buildings and organizations in the event of a pandemic.
- Focusing more energy and resources on those countries where a pandemic is likely to begin.

Area of work 3 – Increase communication and trust between citizens and decisionmakers.

Communication and trust will be essential for dealing effectively with a pandemic. Citizens need to be able to get critical information about the disease, and if they do not trust the scientists and public officials who are making decisions in a crisis, they will not heed emergency plans and procedures. Press releases and media advisories are not enough: we need to build better lines of communication on the Internet and through the workplaces, organizations, and other groups that people belong to. Health agencies should reach out more proactively through these networks in order to inform people and involve them in talking about these issues. Public officials should ask for more citizen input on health policy decisions. The groundwork must be laid before a pandemic occurs, so that the public response to the crisis can be well-coordinated and broadly supported.

Possible action items under this approach:

- Using the Internet and mass e-mail distribution lists to provide information about pandemic response.
- Meetings between health officials and media outlets to discuss the possibility of a pandemic.

- Collaboration between health agencies and a wide variety of community organizations – churches, businesses, nonprofits – to spread information and to recruit participants for citizen involvement efforts.
- Various kinds of citizen involvement efforts so that people can give input on health policy decisions and talk about other ways to take action on these issues.

Discussion questions on the approaches:

- 1. What other approaches would you add? What is missing?
- 2. Which of these approaches seem the most promising to you? Why?

Part 2 – Thinking about ways to make a difference

(15 minutes)

Break into groups of two or three people.

- 3. Think about action ideas that you believe would work. You might talk about ideas that were mentioned in Sessions 1 or 2, or you might invent new ideas. They can be big ideas or small ones.
- 4. Of all the ideas, which ones seem best? Why? Try to settle on two or three.

Come back together in the whole group.

- 5. Start by looking at the action ideas you have listed. If some of the ideas are nearly alike, combine them.
- 6. Narrow down the list to no more than four ideas.

Part 3 – Final questions (15 minutes)

- 7. [For the recorder:] What were some of the main themes and action ideas from the discussion?
- 8. [For the group:] Were there any other themes or action ideas that should be listed in the group record?
- 9. What have you learned today? What will make the biggest impact on how you think and act?
- 10. Is there an action idea that you want to work on, either as an individual or as part of a group?
- 11. What do you value most about today's discussion? About the forum as a whole?
- 12. What worked well? What did not work well? What would you add or change?

Assumptions that went into developing the list of goals for Session 2:

- We face a moderately severe pandemic in the U.S., with half a million deaths and two million hospitalizations.
- All age groups are attacked equally by the virus.
- Death and hospitalization rates most likely will be highest in infants under 1 and persons 65 and older, but could vary from these past patterns.
- Antivirals are adequate only to treat the very sick, not for prevention.
- There are very limited supplies of vaccine in the early days of the pandemic perhaps only enough to vaccinate three million persons per month, starting 3-6 months after the pandemic begins, or up to 18-27 million persons in the first year of the pandemic.
- Because of limited supplies, the groups must be vaccinated in sequence one after another in priority order.
- If supplies are adequate to allow coverage of more than one group, then these could be vaccinated simultaneously in any order.
- Vaccination is distributed at the same time to all states across the country based on population size.
- Vaccine is used to protect the persons it is given to or their close contacts, and not primarily to decrease transmission in the general population.
- Vaccine is used only in persons for whom it works well.
- Vaccine is not used in nursing home residents.
- Guidance about who first to vaccinate comes from the federal government.