

**H1N1 Vaccination Program: Public Engagement Meetings  
Facilitator Worksheets for Small Group Discussion  
Sacramento, August 15, 2009**

**Introduction**

On August 15, 2009, X members of the public met in Sacramento to learn about the H1N1 virus and hear a presentation about the decisions already made about vaccination. At the request of the Centers for Disease Control and Prevention, they discussed a set of decisions that will have to be made in the very near future about the vaccination program. These decisions were encapsulated in three scenarios representing three different levels of effort by public agencies, clinics and service providers in making vaccine available.

**Option 1 – Go Slow**

- A few additional sites added to seasonal flu sites
- Goal to meet an expected low public demand for vaccine
- No rush to vaccinate early on
- Slight increase in communication
- Slight increase in volunteer involvement
- Slight increase in partnerships
- Slight increase in safety, disease, and coverage monitoring

**Option 2 – Moderate Effort**

- Goal to promote vaccination to eligible groups, set up extra vaccination sites beyond those used for a regular flu year, and vaccinate a large number of the eligible groups relatively quickly
- Aim to raise the expected low public demand for vaccine
- Enhanced communication
- Enhanced volunteer involvement
- Enhanced partnerships
- Enhanced safety, disease, and coverage monitoring

**Option 3 – Full Throttle**

- Significant additional federal, state, and local funds invested in creating numerous extra vaccination sites in both the public and private sectors
- Aim to create and respond fully and speedily to significant public demand for vaccination even if the severity of the illness is initially perceived to be low
- Extensive communication activities to stimulate public demand
- Extensive networks of volunteers and partners are identified and ready to spring into action
- Aggressive monitoring of safety, disease, and coverage to collect timely data and take any corrective actions needed to improve the program or protect public safety

## **Public Viewpoints – What matters most to you in connection with a vaccination program?**

The Sacramento discussions tended toward the two outside options – between a set of reasons to go full-throttle and a set of reasons for going slow. For a full-throttle approach, the group begins with overarching goals of preventing flu deaths, controlling infectious disease and protecting the maximum number from the risk of getting H1N1 virus. Those participants who are most inclined to a full-throttle approach included these reasons, among many, for their preference:

- The need for substantial communication, awareness, and information, including combating false information
- Empowering free choice and informed consent
- Educating about ways other than vaccination to prevent the flu
- Protecting the high-risk population
- Increasing the likelihood that those who are vaccinated will receive the booster
- Accessing hard-to-reach populations including non-English speakers and answering social justice and equal access issues

The full-throttle approach was tempered significantly with the group's assessment that California health agencies will be unable to execute a full-throttle approach given extraordinary budget cuts and cost constraints.

The go-slow discussion focused on a set of implementation and vaccine safety concerns, including:

- Vaccine-related side effects and adverse events caused by vaccination
- Uncertainty about the ability of state and local health agencies to apply the necessary resources for anything other than a go-slow approach
- The press of other health issues that are competing for those same limited resources
- Uncertainty about the severity of the outbreak in the coming flu season

In addition, the go-slow discussion moved in each group to the need for education, trustworthy data sources, a wide distribution of credible information that can reach across a very diverse population, and the need to build understanding about all of the issues rather than simply making a case for vaccination.

After the participants deliberated about going slow or moving at a full-throttle pace, most expressed a preference for an intermediate approach. For many, that represents a blended approach of significant data sharing and education with caution about vaccination itself. For some, it represents a full-throttle aspiration tempered with an admission that the implementation constraints make a full-throttle approach unlikely or even impossible. A set of participants held fast to a go-slow approach and a different set held on to a full-throttle; in both cases, this was about ten percent of the participants.

### **Public Viewpoints – What changed your perspective?**

When asked whether they heard something during the day that opened up their thinking or caused them to think differently than what you were thinking before the meeting, four participants offered these observations:

- ◆ Surprised that seniors are not most at risk
- ◆ Impressed by the fact that CDC is holding these meetings and asking for public opinions
- ◆ Surprised at how much of the conversation focused on the complicating factors of culture, race and geography and of the complications posed by these variables
- ◆ Impressed by the level of information in the discussion about risks and side effects

### **Electronic Poll**

Participants registered their opinions in an anonymous, electronic poll focused on both the three levels of effort and the underlying values. The moderate level received the majority of the group's support. The go-slow approach received the lowest level of support in the primary poll.

The majority preference for an intermediate approach remained in place whether the outbreak is presumed to be less severe than expected or to be more severe than expected. Interestingly, 11% of the participants stay with a go-slow approach in a more severe outbreak and 11% stay with a full-throttle approach in a less severe outbreak.

I Prefer Option 1 – Go Slow	15%
I Prefer Option 2 – Moderate Effort	57%
I Prefer Option 3 – Full Throttle	28%
Totals	100%

If less severe

I Prefer Option 1 – Go Slow	33%
I Prefer Option 2 – Moderate Effort	56%
I Prefer Option 3 – Full Throttle	11%
Totals	100%

If more severe

I Prefer Option 1 – Go Slow	11%
I Prefer Option 2 – Moderate Effort	47%
I Prefer Option 3 – Full Throttle	42%
Totals	100%

In the poll of values statements, the results were these:

	First Choice	Second Choice	Third Choice
Protect maximum number from the risk of getting the flu caused by the H1N1 virus	35	33	26
Protect maximum number from possible vaccine side effects (lack of trust in vaccine safety)	11	19	26
Limit expenditure of government resources	4	9	12
Flu caused by the novel H1N1 virus won't be as severe as predicted	5	4	15
I want to allow for maximum education and testing	41	29	16
Limit government role in health care decision (lack of trust in government in this arena)	4	6	5
Totals	100%	100%	100%

### **Polling Discussion**

The participants offered these reactions to the polling:

- ◆ Despite the fact that the earlier discussion had focused on the serious budget problems facing state and local governments in California, cost was not an important reason for level-of-effort preferences.
- ◆ The prospect of federal resources may have made that difference.
- ◆ There may be a problem in the logic behind a full-throttle on communication and education paired with a go-slow for vaccination: the communication and education will create a demand that will move vaccination away from go slow or will result in a mismatch between a high demand and a low level of infrastructure to meet it.

## **Primary Concerns/Interests**

In their small groups, the participants enumerated these interests/concerns/needs:

### *Public Health and Safety Focus*

- ◆ Need to focus on a societal responsibility for society's health
- ◆ Fulfill a duty to public safety and health
- ◆ Concern about maximizing benefits/saving lives and minimizing risks
- ◆ Some are concerned that those who would want to be vaccinated won't have access and others are concerned that those who don't want to be vaccinated will be coerced into being vaccinated

### *Proportional Response*

- ◆ There is a need for a proportional response (not to overreact to the upcoming flu season)
- ◆ Concern about overhype from media and public health
- ◆ Concern that a full-throttle approach will create an inappropriate level of public concern/fear

### *Resources*

- ◆ The full throttle approach is good for education and communication; however without local resources, full throttle is unlikely
- ◆ Government funding will be limited in Sacramento unless federal funds close the gap
- ◆ Concern over the cost of administration and the inability of some to pay

### *Tradeoffs*

- ◆ Risk of drawing attention away from other health concerns: obesity, smoking, diabetics

### *Communication*

- ◆ Need to avoid scare tactics that cause people to feel coerced into getting the vaccine
- ◆ Full disclosure of data is important – risks and benefits
- ◆ Need to effectively communicate accurate information to target populations, to those with limited English language skills and those with low literacy
- ◆ Important to find approaches that communicate the issues effectively
- ◆ Need for culturally-competent education
- ◆ Challenge of communicating the need for vaccination to the younger, high-priority populations
- ◆ Need to present prevention information (hand washing, etc.)

### *Informed Consent/Freedom to make one's own informed decision*

- ◆ Personal choice is essential
- ◆ Need for full disclosure of information

- ◆ As a point of personal accountability, the public should be given all of the information necessary to make their own choices
- ◆ Program goal should be to empower individual decision making

#### *Trust and Safety*

- ◆ Concern over safety and vaccine side-effects
- ◆ Need to address the lack of trust in information about vaccination
- ◆ Risk/Benefit analysis for vaccine safety seems incomplete or flawed
- ◆ Concern about the credibility of the information that leads to the vaccination program decision making
- ◆ Liability coverage for vaccine companies reduces trust in vaccine safety
- ◆ Full transparency and public access to information is essential

#### *Access and Fairness*

- ◆ Equal access and availability are important
- ◆ Fairness in communication, in vaccine availability and in vaccine administration are important
- ◆ Need to examine the vaccination program strategies through a social justice lens
- ◆ Some are concerned that those who would want to be vaccinated won't have access and others are concerned that people will be coerced into being vaccinated
- ◆ Need to effectively communicate accurate information to target populations, to those with limited English language skills and those with low literacy
- ◆ Important to find approaches that communicate the issues effectively
- ◆ Need for culturally-competent education

### **Program Options – Pros and Cons**

In deliberating on the three levels of effort, the participants enumerated these advantages and disadvantages of each:

#### **Full Throttle**

- Pros
  - Protects public health/safety
  - Best level of outreach, communication and education to all
  - Combats false information
  - Allows for education about prevention
  - Maximizes community-wide education
  - Protects high-risk populations
  - Increases the likelihood of getting the booster
  - Provides access to hard-to-reach populations
  - Increases population-level immunity
  - Reduces deaths
  - Responds appropriately to the risk for most likely to get sick
  - Improves convenience for those wanting the vaccine
  - Increases safety monitoring and disease surveillance

- Reduces the number of wasted doses
  - Advantages those with limited information
  - Allows for valid information to enter the discussion
  - Standardized/correct information
  - May reduce overall health costs as emergency room visits and hospitalizations are decreased
  - Can reach those who live in communal living spaces (dormitories, etc.)
  - May prevent pandemic
  - May speed up healthcare reform
  - May reduce the numbers of healthcare workers who will miss work due to illness
- Cons
    - Not able to pay for this level of effort
    - Not enough staff to make this happen
    - Could be an overreaction
    - Makes tracking side effects more difficult
    - Could lead to vaccine scarcity
    - May lead to second-dose scarcity
    - May reduce public trust
    - Makes it impossible to conduct a separate educational effort first
    - Could overwhelm public resources due to fear
    - Prevents the opportunity to study the true effects
    - Could create panic
    - Would entail a complicated media campaign
    - Will leave low-priority groups with demand but no supply
    - Will exacerbate the suspicion of government
    - Reduces the opportunity to evaluate the safety of vaccine
    - If done too fast and H1N1 not as severe as predicted, then the public would be more skeptical of government
    - If there are side-effects, there could be backlash as in the 1970s.
    - Increases the risk of using resources unnecessarily
    - Increases the risk of averse effects due to lack of time to insure safety through further research/testing
    - Increases the risk of targeted discrimination for those who refuse the vaccine

Moderate

- Pros
  - Is appropriate level of outreach and education
  - Is realistic
  - Allows for education first
  - Reduces the likelihood of sensationalism in media
  - Is more flexibility
  - Responds to flu as it happens
  - Allows for the best use of money (allows health agencies to address other health problems)

- Advocate for resources, volunteers
  - Can lead to an increase in seasonal flu vaccinations
  - Makes it likely that people will get the second dose
  - Allows for the possibility of moving to a full-throttle approach if necessary
  - Eliminates the need to take extreme measures unnecessarily
  - Can lead to a public perception that this is more serious than the seasonal flu
  - Allows for targeting resources to where they are needed most
- Cons
    - Triggers the trust issues
    - Could lead to vaccine side effects
    - Could be too-little-too-late
    - May still cost more than local governments have available
    - May not reach those hardest to reach
    - Could lead to vaccine shortages
    - Run out of vaccine
    - May keep those aged 65 and over from having access
    - May not allow for ramp-up if outbreak is more severe
    - May lead the public to conclude that too little is being done

#### Go Slow

- Pros
  - Responds best to the lack of government resources in California
  - Empowers personal decision making
  - Responds best to the need to monitor side effects
  - Allows for resources to be allocated to other pressing problems
  - Avoids panic, especially among those not at risk
  - Allows for time to craft outreach and education messages
  - Limits to federal spending
  - Allows to evaluate safety of the vaccine
  - Adequate to the need because it uses seasonal flu vaccination site
  - Reduces the risk of negative side effects affecting large populations
  - Reduces the changes of injuries due to side effects
  - Satisfies those who do not want more government involvement in health care
- Cons
  - May not be enough to be effective
  - Would be difficult to respond if a stronger response is needed
  - Is insufficient for the level of education needed
  - Would not be enough if the outbreak is more severe
  - Plays into myths of government conspiracy
  - If no contingency is included, could be insufficient
  - Would not serve seniors and other non-target groups
  - Doesn't allow for correcting misinformation
  - Could lead to preventable deaths
  - Would not provide population-level immunity

- Would not reach the uninsured, those in congested housing, dorms, etc.
- Could create a public perception that the flu is not serious
- Could miss the window of time to administer the vaccine before the influenza spreads
- Risks an increase in costs and resources for treatment if the flu spreads

Preliminary Draft