

**H1N1 Vaccination Program: Public Engagement Meetings
Facilitator Worksheets for Small Group Discussion
Bucks County, PA
August 22, 2009**

Introduction

On August 22, 2009, ninety-seven members of the public met in Bucks County, PA 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.

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

Participants spoke most about the need for more information shared with the public on the virus, vaccination risks (including side effects) and prevention methods in simple language. The group stressed the importance of vaccine safety, the lack of time for thorough trials, the need for a reporting system for adverse events and a lack of trust in the government and the pharmaceutical companies that manufacture and test the vaccine. The participants also talked about ensuring that the vaccine is available (without adjuvants) with education on side effects and prevention measures. Lastly the group discussions focused on the need to base vaccination decisions on sound science and not politics.

Electronic Poll

Participants registered their opinions in an anonymous, electronic poll focused on both the three levels of effort and their underlying values. The moderate level of effort received the most support. If the outbreak was less severe, the majority preferred the go-slow approach. If the outbreak is more severe than estimated, half supported a full-throttle approach.

Preferred Options

I Prefer Option 1 – Go Slow	24	31.17%
I Prefer Option 2 – Moderate Effort	36	46.75%
I Prefer Option 3 – Full Throttle	17	22.08%
Totals	77	100.00%

If less severe

I Prefer Option 1 – Go Slow	42	53.85%
I Prefer Option 2 – Moderate Effort	34	43.59%
I Prefer Option 3 – Full Throttle	2	2.56%
Totals	78	100.00%

If more severe

I Prefer Option 1 – Go Slow	17	20.73%
I Prefer Option 2 – Moderate Effort	24	29.27%
I Prefer Option 3 – Full Throttle	41	50.00%
Totals	82	100.00%

Value Statements

The value statements that were most often selected as a priority were:

“I want to protect the maximum number from possible vaccine side effects (lack of trust in vaccine safety)” was in the top three for first, second and third priority; 20.99% said first priority (2nd), 20.25% said second priority (1st), and 17.50% said third priority (1st).

“I prefer an approach that allows some flexibility and is easiest to ramp up or down to be responsive” was in the top three for first, second and third priority; 27.16% said first priority (1st), 12.66% said second priority (3rd), and 13.75% said third priority (2nd).

“I want to prevent the maximum number of deaths and hospitalizations caused by H1N1” was in the top three for both second and third priority; 13.92% said second priority (tied for 2nd) and 13.75% said third priority (2nd).

First Priority – All (in order of preference)

I prefer an approach that allows some flexibility and is easiest to ramp up or down to be responsive	22	27.16%
I want to avoid as many vaccine side effects as possible	17	20.99%
I prefer to be as prepared as possible in advance of the epidemic	11	13.58%
I want to prevent the maximum number of deaths and hospitalizations caused by the novel H1N1	8	9.88%
I want to allow more time for testing larger numbers of people with novel H1N1 vaccine	8	9.88%
I prefer a balanced approach that includes some of the advantages of the other two approaches	7	8.64%
Lack trust in government sponsored programs	5	6.17%
I want to avoid the costs associated with the loss of life and hospitalizations	3	3.70%
I want to spend government resources for other more pressing needs	0	0%
I want to avoid unduly alarming the population	0	0%
Totals	81	100%

Second Priority – Top Four (in order of preference; see appendix B for all results)

I want to protect the maximum number from possible vaccine side effects (lack of trust in vaccine safety)	14	20.25%
I prefer a balanced approach that includes some of the advantages of the other two approaches	11	13.92%
I want to prevent the maximum number of deaths and hospitalizations caused by the novel H1N1	11	13.92%
I prefer an approach that allows some flexibility and is easiest to ramp up or down to be responsive	10	12.66%

Third Priority – Top Four (in order of preference; see appendix B for all results)

I want to protect the maximum number from possible vaccine side effects (lack of trust in vaccine safety)	14	17.50%
I want to prevent the maximum number of deaths and hospitalizations caused by the novel H1N1	14	17.50%
I prefer an approach that allows some flexibility and is easiest to ramp up or down to be responsive	11	13.75%
I want to avoid unduly alarming the population	9	11.25%

The polling results are consistent with conclusions of the small-group discussions. An expanded statement from the small-group discussions follows.

Other Purposes for the Vaccine Program

Working from a list of eight additional goals, participants registered preferences for a first, second and third choice. The other purposes most often selected as a priority were:

“None of these (if you are opposed to the vaccination program, you can select this on each time)” was in the top three for first, second and third priority; 15.58% said first priority (3rd), 19.44% said second priority (3rd) and 23.68% said third priority (1st).

“I want a vaccination program that gives everyone an equal chance of being vaccinated regardless of age or risk status” was in the top three for first and second priority; 18.18% said first priority and 22.22% said second priority (tied for 1st). This purpose tied for 4th as the third priority.

“I want to allow more time for educating the populations and raising awareness about H1N1” was in the top second and third priority; 22.22% said second priority (tied for 1st) and 17.11% said third priority (2nd). This purpose was 4th as the first priority.

Other Purposes - First Priority (in order of preference)

I want to protect the maximum number of persons from just getting sick from H1N1 in the first place.	33	42.86%
I want a vaccination program that gives everyone an equal chance of being vaccinated regardless of age or risk status.	14	18.18%
None of these (If you are opposed to the vaccination program, you can select this one each time.)	12	15.58%
I want to allow more time for educating the population and raising awareness about H1N1 virus.	11	14.29%
I want to make sure to protect the subgroups in the population who have been traditionally underserved.	2	2.60%
I want to protect our citizens but also conserve vaccine for donation to other poor countries which need vaccine.	2	2.60%
I want to accelerate vaccine availability before all testing is completed.	2	2.60%
I want a vaccination program on a first come first served basis while supply is limited.	1	1.30%
Total	77	100%

Other Purposes – Second Priority – Top Four (in order of preference; see appendix B for all results)

I want to protect the maximum number of persons from just getting sick from H1N1 in the first place.	33	42.86%
I want to allow more time for educating the population and raising awareness about H1N1 virus.	16	22.22%
I want a vaccination program that gives everyone an equal chance of being vaccinated regardless of age or risk status.	16	22.22%
None of these (If you are opposed to the vaccination program, you can select this one each time.)	14	19.44%

Other Purposes – Third Priority – Top Three (in order of preference; see appendix B for all results)

None of these (If you are opposed to the vaccination program, you can select this one each time.)	18	23.68%
I want to allow more time for educating the population and raising awareness about H1N1 virus.	13	17.11%
I want to make sure to protect the subgroups in the population who have been traditionally underserved.	11	14.47%

Small-Group Discussions – What are your main concerns related to an H1N1 vaccination program?

General Safety

- Need thorough testing of the vaccine – duration of testing and number or people tested.
- Need more information of what to expect regarding side effects and the 2 doses.
- Vaccine has not been fully tested and the risks are not known.
- Non-pharmaceutical interventions have not been fully promoted or explored.
- Need results from clinical trials; “do no harm” until you know outcome.
- Concerned about being rushed.
- Adverse side effects need to be reported ASAP (mandatory) to healthcare providers and the public.
- Concern about the risks of giving the vaccine to pregnant women.
- Concern of the future possibility of mandatory vaccination; needs to remain personal choice
- Need for thorough individual assessment of individualized pros and cons before proceeding with vaccination (personal responsibility/ choice)

Education

- Educate people through [medical] community (doctors, etc) to prevent being contaminated in work environment, schools, and public places.
- Educate the public about the virus and vaccines, including the potential side effects.
- Educate physicians and healthcare professionals, including potential risks of vaccines.
- Provide more education on preventions methods.
- Provide more information and ideas other than vaccinations, i.e. making a “flu season recommendation” to employers to make it easier for people to stay home when sick.
- Provide quality and accurate information from independent sources; concerned about the quality of the information itself.
- Demonstrate the actual severity of the virus (i.e. severity beyond the seasonal flu).
- Educate food service industry/ movers to prevent spread.
- Provide public schools with accurate and reliable information about risks, benefits, cost, and agencies involved in the vaccine.
- Make available sufficient information about side effects from clinical trials.
- Use education opportunities to best advantage (other vaccines or viruses, other public safety issues).
- Use media outlets.
- Avoid creating public panic.
- Report adverse events in a timely manner to the public

Preparedness

- Ability of government to ramp up for a serious outbreak
- False dichotomy between slow and intermediate approaches because it underestimates U.S. ability to be resilient and respond quickly.
- Having enough supply for priority groups.

Distrust

- Afraid government is pushing too hard, too much hype; there should be more factual info, less hype.
- Distrust of government and of information being provided. Need information to come from independent sources of reliable info (distrust of media reporting, government, drug companies).
- Distrust the pharmaceutical companies sponsoring the vaccine trials
- Distrust the vaccine program will remain voluntary.
- Distrust the vaccines will not include adjuvants; feel there is a very high probability that they will be added.
- Distrust lack of liability on the part of manufacturers of vaccines.
- Liability- given limited testing/ risk information.
- Capacity to deliver- can pediatricians handle it?
- Resources may be there, but administrative structures not sufficient to handle.

Emphasis on Prevention and other aspects

- Government discounts natural remedies; it should push prevention and alternatives (personal hygiene).
- Money should be dedicated to prevention.
- Balanced education program: prevention, personal responsibility.
- Focus is too much on the pharmaceutical and not enough on the education and non-pharmaceutical.

Other

- Additional research on shedding should be conducted and shared.
- Provide vaccine for those in the US population before making the vaccine available for other countries.

Pros and Cons of Each Alternative

There was no consensus among the small groups on which approach is best. The following list of options (pros and cons) is in order of overall popularity, but not consensus or majority.

Pros and Cons of an Intermediate Approach

Pros

- Allows for time to provide more information and education
- Costs is less than Full Throttle approach (conserves resources)
- Strikes balance between costs and need for information
- More flexibility in regards to preparedness and implementation
- Time for balanced complete education
- Leaves wiggle room for vaccine production if needed
- People don't feel forced – they have a choice

Cons

- Too slow if outbreak is severe
- State cooperation is needed
- Not enough man power to handle epidemic
- Non-committal
- Vaccine not tested enough

Pros and Cons of a Go-Slow Approach

Pros

- Safest Approach because of insufficient testing to date
- Less Expensive
- Avoids mass hysteria. Minimizes possible resentment of public because no one feels pressured or scared
- Lower risk of side effects with an untested vaccine
- The government will be less involved (mistrust of government issues)
- More time to gain knowledge of risks and benefits
- State cooperation not needed

Cons

- Doesn't immunize enough people soon enough
- May be too little too late
- May not have enough vaccines
- Lack of education provided to public
- Private providers can not purchase the vaccine
- May not be ready for the severity of the disease

Pros and Cons of a Full-Throttle Approach

Pros

- Reduce risk of infection in population
- Better to be safe than sorry
- Requires increased education
- Assures target population will receive vaccine

Cons

- There is more pressure for individuals to receive vaccination if large amount is available
- This approach might go overboard with resources
- There may not enough time to educate before implementation
- Cooperation is needed on local, state and federal levels
- Lack of education on vaccine safety and general H1N1
- Lack of trust of government
- No proof the vaccine is safe (little time for vaccine testing)
- Turns medical problem into political issue
- Possible hysteria and fear with large supply of vaccine being produced.

APPENDIX A: Demographics of Participants

Total: 64 people

Age Range:

18-30 years	8	8%
31-50 years	24	25%
51 and above	63	66%

Gender:

Male	46	48%
Female	50	53%

Ethnicity:

Asian or Pacific Islander	1	1%
Mixed Race	2	2%
Black (or African American)	3	3%
Hispanic or Latino	1	1%
White	87	92%
Other	6	6%

Appendix B: Polling result for Values and Other Purposes

2009 Vaccination Program Preference	Responses					
	First		Second		Third	
I want to avoid as many vaccine side effects as possible.	17	20.99%	16	20.25%	4	17.50%
I want to allow more time for testing larger numbers of people with the novel H1N1 vaccine	8	9.88%	2	2.53%	3	3.75%
I want to spend government resources for other more pressing public needs.	0	0.00%	2	2.53%	7	8.75%
I want to avoid unduly alarming the population.	0	0.00%	9	11.39%	9	11.25%
I lack trust in government sponsored programs	5	6.17%	6	7.59%	5	6.25%
I prefer an approach that includes some of the advantages of two approaches (full-throttle on some things, go-slow on others).	7	8.64%	11	13.92%	7	8.75%
I prefer an approach that allows some flexibility in response to changing characteristics of the epidemic.	22	27.16%	10	12.66%	1	13.75%
I want to prevent the maximum number of deaths and hospitalizations caused by the novel H1N1 virus.	8	9.88%	11	13.92%	4	17.50%
I prefer to be as prepared as possible in advance of the epidemic.	11	13.58%	8	10.13%	7	8.75%
I want to avoid the costs associated with loss of life and with hospitalizations.	3	3.70%	4	5.06%	3	3.75%
Totals	81	100%	82	100%	8	100%

2009 Vaccination Program Preference – other goals	Responses					
	First		Second		Third	
I want to protect the maximum number of persons from just getting sick from H1N1 in the first place.	33	42.86%	13	18.06%	10	13.16%
I want a vaccination program that gives everyone an equal chance of being vaccinated regardless of age or risk status.	14	18.18%	16	22.22%	10	13.16%
I want a vaccination program on a first come first served basis while supply is limited.	1	1.30%	1	1.39%	3	3.95%
I want to make sure to protect the subgroups in the population who have been traditionally underserved.	2	2.60%	5	6.94%	11	14.47%
I want to protect our citizens but also conserve vaccine for donation to other poor countries which need vaccine.	2	2.60%	4	5.56%	5	6.58%
I want to accelerate vaccine availability before all testing is completed.	2	2.60%	3	4.17%	6	7.89%
I want to allow more time for educating the population and raising awareness about H1N1 virus.	11	14.29%	16	22.22%	13	17.11%
None of these (If you are opposed to the vaccination program, you can select this one each time.)	12	15.58%	14	19.44%	18	23.68%
Totals	77	100%	72	100%	76	100%