Citizen Choices on the National Vaccine Plan

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A Report on the Public Engagement Project on Vaccine Priorities

Collaborating Organizations

Centers for Disease Control and Prevention
Columbus Public Health
Data on the Spot
Department of Health and Human Services, National Vaccine Program Office
FOCUS St. Louis
F.O.C.U.S. Greater Syracuse
Oak Ridge Institute for Science and Education
The Ohio State University College of Public Health
One World Inc.
University of Nebraska Public Policy Center

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The **Oak Ridge Institute for Science and Education** (ORISE) is a US Department of Energy facility focusing on scientific initiatives to research health risks from occupational hazards, assess environmental cleanup, respond to radiation medical emergencies, support national security and emergency preparedness, and educate the next generation of scientists. ORISE is managed by Oak Ridge Associated Universities.

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Executive Summary

Public health decision makers often face situations in which decisions are difficult because competing values, with relatively equal weights, are at stake. Also, many problems today are complex and require the insights of multiple parties to be adequately understood and effectively addressed. The challenge is compounded when data are lacking or uncertain and there is no single scientifically correct decision or policy to be made. Choosing the highest priority activities for the National Vaccine Plan is such a situation. Most often in the past, such decisions have been made with the benefit of advice from a selected sample of representatives of stakeholder organizations who by their very nature have vested interests. Although such stakeholders are often experts and their input is useful and important, their advice can lack impartiality and representativeness and is often provided without consideration of the other values also relevant to decision making. Obtaining the input and advice of a large and diverse number of individual citizens, who do not represent stakeholder organizations and who in a democracy best reflect public values, provides an overall societal perspective that can contribute to decision making and even can produce innovative solutions and novel policies. The Public Engagement Project on the National Vaccine Plan was carried out to obtain such valuable and unique advice from a large and diverse number of citizens.

Three public engagement sessions were conducted in St. Louis, Missouri, Columbus, Ohio, and Syracuse, New York, in early 2009. A total of approximately 250 citizens—diverse in race/ethnicity, gender, education, and age—participated. In daylong, neutrally facilitated plenary sessions and small groups, citizens learned about the status of the U.S. vaccine system, identified values that were important to them, selected the values that mattered most, and discussed and rated 12 areas of activity proposed in the plan. Based on the strength of the alignment of these proposed areas of activity to the participants' most important values, citizens in at least two of the three cities judged the following to be their top priorities for action:

1. Improve monitoring of disease and vaccines
2. Make vaccines affordable and available to everyone
3. Maintain high rates of vaccination of children
4. Assure there is enough vaccine
5. Improve vaccine safety

In making these choices, citizens reflected core public values centered on achieving equity, protecting the homeland, protecting the most vulnerable, having more education and awareness, and having concern for safety.

This unique advice derived from a large, diverse group of citizens using a series of daylong deliberative processes provides consistent evidence that what matters most to the public about vaccines is post-licensure improvements in their availability and use, especially for children. Proposed improvements in post-licensure vaccination of adolescents and adults and pre-licensure activities, such as research and regulation, greater international assistance with vaccines, and assured compensation for vaccine injuries, were judged to be of relatively less importance. Decision makers choosing priority activities for the National Vaccine Plan are now better informed about what matters most to the public about vaccines and how the public translates these values into proposed actions and policies. Giving citizens this real opportunity to make a difference in their government is well aligned with historic principles of democracy and the current national trend to increase participatory policy making in government.

Introduction

The National Vaccine Program Office (NVPO) of the U.S. Department of Health and Human Services (HHS) is coordinating a revision of the National Vaccine Plan (NVP), last issued in 1994. The 2008 draft strategic NVP (http://www.hhs.gov/nvpo/vacc_plan/2008plan/draftvaccineplan.pdf) was written as an initial step in updating the plan and includes goals, high-level indicators of measurable outcomes, objectives, strategies to achieve each goal, and a vision for the next 10 years in immunization and global health. The draft plan is primarily the result of deliberation, analysis, and input from multiple federal agencies under the coordination of the NVPO.

Meaningful stakeholder involvement forms a part of the update process. NVPO, with the National Vaccine Advisory Committee (NVAC), is implementing a process to obtain input from a wide range of stakeholders. Several activities are underway to engage expert stakeholders: (1) the Institute of Medicine (IOM) is convening meetings of stakeholders professionally associated with vaccine activities (e.g., pharmaceutical companies, health professionals, and health insurers) to assess plan priorities (see http://www.iom.edu/CMS/3793/51325.aspx); (2) NVAC is staying abreast of developments and will review draft versions of the updated plan; and (3) members of the federal government involved in vaccine-related activities are working with NVAC to identify expert stakeholders and develop mechanisms for soliciting comments from these expert and public stakeholders on the plan.

Meaningful participation by the general public is also important in updating the NVP. NVPO wanted input from the public to obtain feedback on the content of the plan and to identify priorities among the proposed areas of activity in the plan. The public input process is twofold: (1) a public comment period via e-mail regarding appropriateness of the goals and indicators, recommendations for numeric targets for the indicators, and overall vaccine and immunization enterprise described in the draft plan and (2) a series of three public engagement sessions to gain the input of citizens at-large regarding priority areas and public values that underlie the selection of those priority areas.

These sessions provided substantial information on which participants could base their discussions and were an opportunity for a relatively large number of people to exchange ideas, deliberate, and work toward consensus about competing priorities. Additionally, the gatherings provided an opportunity to assess the group output before and after receiving information about vaccines and exchanging perspectives with diverse participants.

Each of the public engagement sessions, conducted in a different city of the country, aimed to convene approximately 100 members of the general public. There, in plenary sessions and small groups, people heard about vaccine-planning issues, identified and prioritized values, and applied those values as criteria to identify the most important proposed areas of activity in the plan.

Technical and logistical assistance was provided by nine organizations as follows:

1. The Centers for Disease Control and Prevention (CDC) provided consultation on the public engagement process.
2. Data on the Spot provided keypad polling technology for immediate feedback from the audience during the engagement sessions.
3. FOCUS St. Louis in St. Louis, Missouri, Columbus Public Health and The Ohio State University in Columbus, Ohio, and F.O.C.U.S. Greater Syracuse in Syracuse, New York, were local host organizations that provided recruitment and small group facilitator recruitment for each session.

4. Oak Ridge Institute for Science and Education (ORISE) assisted in developing, conducting, and reporting the engagement sessions.
5. One World Inc. assisted in designing the engagement process, developing support materials, and facilitating the three sessions.
6. The University of Nebraska Public Policy Center planned and conducted an independent evaluation of all three public sessions. Their report is included as Appendix A to this report.

An NVP Steering Committee, comprised of representatives from the HHS NVPO, CDC, ORISE, and One World Inc., were the key decision makers in the methodology and process design, conduct, and reporting of the sessions.

The objectives of this public engagement activity were to identify and prioritize values that mattered most to citizens in considering the NVP and apply those values as criteria to identify priorities among 12 proposed areas of activity for the NVP. This document reports on the methods, findings, and recommendations of the citizen engagement sessions conducted in St. Louis, Missouri, on March 14, 2009; Columbus, Ohio, on March 28, 2009; and Syracuse, New York, on April 4, 2009.

Methods of Public Engagement

Process Design

Full deliberation includes "a careful examination of a problem or issue, the identification of possible solutions, the establishment or reaffirmation of evaluative criteria, and the use of criteria in identifying an optimal solution" (Gastil 2000, 22). In this public engagement project, the public's values were identified and used as evaluative criteria; the possible solutions were a pre-identified set of 12 proposed vaccine activity areas (table 1) derived from the five goals and the 36 objectives included in the draft plan.

Table 1. Proposed Areas of Activity for Prioritization

1. Improve tools for making vaccines.
   Improve ways to develop, make and test new vaccines.

2. Increase vaccination of adults.
   Doctors suggest adults get vaccines for seasonal flu and other illnesses. Many adults don't get these vaccines.

3. Increase vaccination of adolescents.
   Doctors suggest 9-18 year-olds get vaccines. These include vaccines against meningitis (swelling of the brain) and Human Papilloma Virus (HPV, a cause of cervical cancer). Vaccination rates are low.

4. Make vaccine affordable and available to everyone.
   Help make vaccines available to those who cannot afford them. This includes people of all ages. It also includes groups with special needs such as those in nursing homes and others at high risk.

5. Maintain high rate of vaccination of children.
   Doctors suggest children get vaccines against 14 diseases before two years old. Vaccination rates are high. The goal is to help ensure that they stay high.

6. Develop new vaccines.
   Develop vaccines for such diseases as HIV/AIDS and malaria.

7. Assure there is enough vaccine.
   Improve systems that manufacture and distribute vaccines. This is to help avoid shortages like the one that occurred with the flu shots several years ago.

8. Improve vaccine safety.
   Learn more about the causes of side effects. Develop ways to predict who will have bad side effects. Improve ways to identify and respond to vaccine safety issues.

9. Assure compensation for those injured by vaccines.
   Continue and improve the government system for compensation. The system identifies and pays money to people harmed by vaccines.

10. Help other countries reduce diseases through vaccination.
    Help current programs such as those to get rid of polio and control measles. Help provide vaccines that the U.S. already has to countries that do not have them. Develop new vaccines for major health problems in other countries such as malaria.

11. Improve monitoring of disease and vaccines.
    Measure vaccine success by counting the number of people getting vaccines and those still getting sick from the diseases the vaccines would prevent.

12. Improve the information offered about vaccines.
    Improve the information offered about vaccine benefits and risks. This will help doctors, patients, and policy makers make decisions.

First, to help inform the methods of the engagement sessions, four focus groups of 1-1/2 hours each were conducted in Chicago, Illinois, on October 30, 2007, with a total of 35 participants representing diverse race/ethnicities, gender, and age. Participants were asked to rank the importance of 11 proposed vaccine topic areas developed by NVPO and ORISE and generate a list of values on which they would base their decisions regarding those topic areas. These focus group values guided the development of values for this project (table 2).

Table 2. 2007 Focus Group Results

Highest-ranked topic areas

make vaccines available and affordable to everyone
maintain a high rate of vaccination for children
develop new vaccines
assure there is enough vaccine
improve vaccine safety

Underlying values

vaccine safety	education	children
social equity	global issues	

Then, to get more specific prioritization than at the goal level but not overwhelm citizens with the details of the specific 36 objectives and 156 strategies, the steering committee developed areas of activity based on the five goals and 36 objectives of the draft plan. These activity areas are listed in table 1.

To establish values as evaluative criteria, an activity based on the "Q methodology" (www.qmethod.org) was developed to examine how people think about values that matter most to them when considering the NVP. In the Q-sort type of exercise, participants were given a set of values (see table 3) and one-sentence examples (individually on cards) and were asked to sort the items on the cards in terms of their degree of importance into three piles ("what matters most," "what matters least," and "the rest").

Table 3. Public Values that Participants Considered in Prioritizing Activity Areas

1. Achieving Equity	• Make vaccines easily available and affordable for everyone in the U.S.
2. Protecting Our Homeland First	• Make sure people entering the U.S. are vaccinated, and American travelers are vaccinated before they leave the U.S.
3. Helping Other Countries	• Help poor countries to vaccinate their people. Help make vaccines for diseases common in other countries, but not in the U.S. (such as malaria).
4. Being Vigilant	• Measure how well existing vaccines are working in the U.S. and abroad. Work with others to identify new diseases in the world.
5. Assuring Fairness	• Compensate people injured by vaccines they were required to receive.
6. Emphasizing Safety	• Make vaccines even safer, even if it means that new ones take longer to develop or have to pass tougher tests.
7. Tackling Biggest Problems First	• Invest resources in new vaccines for common diseases, not rare ones.
8. Greater Protection Now	• Work to increase vaccination of teenagers and adults. Make better use of existing vaccines to protect more people.
9. Improving Our Science	• Increase research to better understand how vaccines work, and how they can be improved.
10. Promoting Education and Awareness	• Increase awareness of the benefits and risks of vaccines.
11. Securing Supply	• Improve our manufacturing and distribution systems to prevent shortages.
12. Protecting the Most Vulnerable	• Vaccinate persons who have increased risk for bad outcomes from disease, like the young, the old, and those with weak immune systems.
13. Protecting Individuals	• Conduct more research on why some persons have serious side effects and others do not.
14. Reduce Medical Costs	• Develop new vaccines that will help reduce the costs of treating illnesses.

A pretest with non-health-care ORISE employees was conducted on February 18, 2009, to compare this exercise to a free-form generation of values and assess whether the values developed by the Steering Committee resonated with the public and were easy to understand. The activity based on the Q methodology was deemed most effective given the limited time available for the activity during the planned dialogue sessions. Following the pretest and first engagement session in St. Louis, minor refinements to the 14 values in table 3 were made to improve clarity of the values generation activity.

Finally, a matrix activity was developed to allow participants to rate areas of activity based on their strength of alignment to the values (on a scale of one to five, with one suggesting the weakest alignment and five the strongest alignment). See matrix (table) activity in Appendix B.

Recruitment

At each location, local host organizations recruited participants. The organizations were FOCUS St. Louis, Columbus Public Health, The Ohio State University College of Public Health, and F.O.C.U.S Greater Syracuse.

Each host organization recruited participants through databases of local partners (e.g., local health departments, schools, and other community organizations) and citizens who have previously participated in or indicated interest in such public engagement activities. Hosts used e-mails, newsletter announcements, phone calls, flyers, and Web pages to advertise the event. The goal for recruitment was 100 citizens; organizers believed that having at least this number of citizen participants would help ensure diversity and add credibility and legitimacy to the results. The number of citizens participating is shown in table 4.

In an attempt to standardize the screening and recruitment processes, host organizations were provided the screening instrument in Appendix C. All participants recruited were at least 18 years of age and comfortable conversing in English. Recruitment strived to exclude participants who were physicians, nurses, or media professionals.

Participants were provided a cash incentive in St. Louis and Columbus.

Table 4. Number of Citizen Participants by Community

City	No. of Participants
St. Louis, Missouri	97
Columbus, Ohio	98
Syracuse, New York	54
Total	249

Table 5. Comparison of Participant Demographics to U.S. Demographics

Demographic Variable	Participants	U.S. Demographics
Gender		
Females	68.4%	50.8%
Males	31.6%	49.2%
Age		
18–24	10.0%	13.1%
25–34	15.3%	17.8%
35–44	15.8%	19.4%
45–54	23.0%	19.2%
55–64	20.6%	14.0%
65+	15.3%	16.6%
Race/Ethnicity		
Hispanic White	5.4%	14.7%
Hispanic Black	6.9%	
Non-Hispanic White	46.5%	66.3%
Non-Hispanic Black	34.7%	12.2%
Asian	1.0%	4.3%
Native American	2.5%	0.7%
Other	3.0%	1.9%
Education		
Less than high school	3.3%	6.5%
Some high school	9.1%	9.5%
High school graduate	16.3%	30.0%
Some college	25.8%	19.6%
College graduate	19.1%	24.5%
Some graduate school	7.2%	
Graduate school graduate	19.1%	9.9%

Facilitation

Plenary portions of the day were guided by one facilitator, Ms. Jacquie Dale of One World Inc. Small-group facilitators were recruited from within the host organizations or local partners (e.g., community organizations, local health departments, and universities) and were generally required to have previous facilitation or public engagement experience. Steering Committee representatives met with small-group facilitators on the day before the session, reviewed the plan for the day, answered questions, and otherwise prepared the facilitators. Additional telephone briefings were provided for the facilitators in Columbus and Syracuse a few days prior to the sessions.

Demographics of Participants

The demographic characteristic of those participating in all three sessions and a comparison to U.S. demographics are presented in table 5. A goal of the project was to attract a diversity of participants, both in terms of demographic characteristics and interests, to hear multiple perspectives from different sectors of the population. Local host organizations successfully recruited participants of diverse backgrounds and perspectives. Participants were predominantly female for the three meetings. Participants represented a cross section of ages, although a majority of participants were over 44 years of age. There was a mix of racial and ethnic diversity across the three sites. Overall, participants in the three meetings represented diversity in level of education, although the majority in each meeting had at least some college experience. For additional demographic information, see the project evaluation report in Appendix A.

The Engagement Process

These public engagement sessions were conducted at each location from 8:30 a.m. to 4:30 p.m. The agenda for the day and facilitation script are presented in Appendix B. Participants were assigned seats at round tables accommodating approximately 8–10 people each to help ensure demographic diversity with small discussion groups.

Citizens were engaged for a full day of intense dialogue and deliberation about priorities for the NVP and their underlying values. In the morning plenary session, participants learned about vaccines and the current vaccine program in the U.S. and abroad through a presentation delivered by William Atkinson, M.D., MPH, CDC, or Raymond Strikas, M.D., NVPO. The information they received was reinforced with additional handouts (see Appendix D), and participants asked any remaining questions of Drs. Atkinson or Strikas and other subject matter experts following their presentations.

In the morning small-group sessions, citizens discussed their values and prioritized those that mattered most to them when considering the new vaccine plan at both the table level (one vote per table) and individual level (one vote per individual). The top four to five values were selected from individual votes (see findings in table 6). St. Louis participants voted on their top five values, but, due to time constraints that were realized in the first session, Columbus and Syracuse participants voted only on their top four values. In the afternoon, they learned about the 12 proposed activity areas of the plan through a presentation delivered by Dr. Strikas or Roger Bernier, Ph.D., MPH, CDC, and worked through which areas best fit or aligned with their top values. Participants explored their own views, their table's view, and the full group's ideas about what are the most important proposed activities in the plan. Participants in Columbus also discussed what priority they would give to the areas of activity under a scenario with new money; this activity was not done in the other two cities due to time constraints.

Participants had many opportunities to exchange ideas, deliberate, and work toward consensus at both the small-group and large-group or plenary levels. Participants learning about vaccines and the current vaccine

program created an informed citizen perspective. By the end of the day, priorities emerged about values and which proposed areas of activity citizens would like to see reflected in the government's decision making.

Participant Information

Prior to participating in the deliberations, each participant received an information sheet providing information about the sponsorship of the event, their rights as participants, risks and benefits in participating, and contacts for more information (see Appendix E, Participant Information Sheet).

The Steering Committee developed two presentations for each of the sessions, describing the U.S. vaccine system (presented by either Drs. Atkinson or Strikas) and the priority areas for discussion (presented by either Drs. Strikas or Bernier), as well as a discussion guide with more information for participant reference during the dialogue. The participant handouts are provided as Appendix D.

Circulating vaccine experts or resource people addressed any questions the participants had before, during, and after the session. Approximately three to five vaccine experts (from CDC, NVPO, Health Resources and Services Administration, National Institutes of Health, IOM, and/or NVAC) circulated among the participant groups, answering questions. Several times throughout the day, answers to questions raised in the groups were provided in plenary sessions to help ensure that all participants had equal access to information provided.

Data Collection

Data were collected throughout each session by using the following methods:

1. An *electronic voting system* provided by Data on the Spot captured expressions of value and activity priorities, both as round table groups and as individuals.
2. *Small-group note takers*, either the small-group facilitator or a participant volunteer, captured reflections from discussions on work sheets provided to each group. Key points were also recorded on flip charts.
3. A *plenary session note taker* provided by ORISE captured reflections from plenary discussion.
4. *Evaluation data collection methods* provided by University of Nebraska included pre- and post-questionnaires, focus groups, interviews with local conveners, and interviews with federal policy makers.

Evaluation

A quantitative evaluation assessed citizen perceptions about the deliberation and recruitment processes and knowledge about vaccines through both pre-session and post-session questionnaires. Through focus groups of about six to eight volunteer citizens immediately following each Saturday session, open-ended qualitative questions assessed perceptions about the recruitment process, the quality of the deliberative process, the knowledge they had to engage in informed dialogue, and how their beliefs changed during the meeting. U.S. Census data from the communities within which the three meetings were held also informed how representative of each city's population the participants at each session were. A separate report details the methods, analysis, and results of the evaluation and is included in Appendix A.

Limitations

One limitation of the public engagement project was difficulty in ensuring representativeness of the general public and inclusivity of diverse viewpoints. Due to financial constraints, random representative sampling was not used to assure participants were representative of the community. With the recruitment methods used (e.g., e-mails, newsletter announcements, flyers), individuals self-selected to participate in the public engagement sessions. Also, due to financial and time constraints, only two of four U.S. census regions (Northeast and Midwest) were included in the project.

Findings and Comments

The major findings of this report include (1) values that mattered most to participants related to the new vaccine plan, (2) proposed areas of activity in the plan that best fit with the public's most important values, (3) priority areas in a new money scenario (Columbus only), (4) insights from the dialogue, and (5) messages for plan decision makers.

1. Values that mattered most to participants

Participants voted for the four to five values they think matter most to them and that are the most important ones to underlie the NVP. (As previously mentioned, St. Louis participants voted on their top five values, but Columbus and Syracuse participants voted only on their top four values due to time constraints.) They did this as a table group and then as individuals. Percentage of individuals that voted for a value as one of their top four or five are reported in table 6. Top values, shaded in gray in table 6, varied among cities, but several similarities occurred. "Achieving Equity" was the most frequently cited value in all three cities and the only value voted one of the top four (or five) priorities in all three cities. Four other values were paramount in two out of three cities, including "Emphasizing Safety," "Promoting Education and Awareness," "Protecting Our Homeland," and "Protecting the Most Vulnerable." Two other values were among the most frequently cited in a single city, "Reducing Medical Cost" and "Improving Our Science." Altogether, five values were judged paramount in two or more cities. In general, table groups voted for the same top values (for table vote percentages, see Appendix F).

Table 6. Top Values in an Individual Vote

Table shows percentages of individuals in each city who voted for a value as one of their top five.

	St. Louis (n = 78)	Columbus (n = 80)	Syracuse (n = 45)
Achieving Equity	59%	74%	54%
Emphasizing Safety	60%	21%	51%
Promoting Education and Awareness	55%	28%	58%
Protecting Our Homeland	23%	73%	20%
Protecting the Most Vulnerable	36%	36%	31%
Reducing Medical Costs	12%	44%	18%
Improving Our Science	18%	21%	42%
Securing Supply	7%	29%	20%
Tackling Biggest Problems First	24%	19%	4%
Obtaining Greater Protection Now	14%	19%	16%
Helping Other Countries	17%	10%	16%
Being Vigilant	27%	10%	18%
Protecting Individuals	13%	10%	9%
Assuring Fairness	5%	8%	0%

Comments

Following are reflections on the top values recorded by small-group and plenary group note takers. See tables 7 and 8 for participant quotes captured in plenary- and small-group notes related to the top values.

Achieving Equity

Several participants described achieving equity as all Americans having the equal and affordable opportunity for vaccines, regardless of race, socioeconomic status, and insurance coverage. Other participants described achieving equity as a way to protect the most vulnerable populations, and often the most impoverished and ill, who are without insurance coverage and cannot otherwise afford vaccines. Several participants suggested that the value encompassed other values, such as protecting homeland first. Some described equity as reducing costs (to make vaccines more affordable), while others stressed free vaccine coverage. Some believed achieving equity would result in greater protection of society overall since more people would be vaccinated.

Emphasizing Safety

Emphasizing safety was not voted to the top by some because they had a high level of trust that vaccines in the U.S. are safe or safety is being addressed by the current vaccine system. Other participants did want a priority for all vaccines to be safe. Several participants described emphasizing safety as ensuring that vaccines contain only necessary vaccine components and have no long-term side effects. They referred to a need for education and an informed decision-making process that weighs vaccine risk vs. benefits. Some participants associated this value with "being vigilant" and monitoring vaccines. Several participants discussed a need for constant research and evaluation, and some acknowledged the consequences of a longer research and development phase. Many participants believed in ensuring safety for all, while others emphasized a need to make vaccines safer for children (in particular low birth weight babies, preemies, and those with suppressed immune systems). Safety was associated with concerns for side effects, allergic reactions, vaccine preservatives or additives, and a "too much, too fast" vaccine schedule.

Table 7. Achieving Equity and Emphasizing Safety Quotes

Achieving Equity

"Affordable health care across the board is needed." (St. Louis)

"All can be vaccinated … taxes should cover [the costs], sliding scales." (St. Louis)

"Equity—more those who can't afford food, car payment, or shot." (Columbus)

"If available to all—protect more, make affordable, would get it if it were free." (Columbus)

"Equity is an important value in American society and equity will improve overall protection." (Syracuse)

"Vaccines should be available to all U.S. citizens even if they can't afford the cost of …immigrants." (Syracuse)

Emphasizing Safety

"Constant evaluation needed … to improve vaccine to make people safe from disease." (St. Louis)

"We must ensure safety for all. Children are a priority." (St. Louis)

"What are the long-term consequences of vaccinations? How do they hurt? How do they help?" (St. Louis)

"Vaccine safety is scary. [People need] to read … when [they] take family to get shots." (Columbus)

"Let other countries help us make it better… helping us improve the vaccine and … test it." (Columbus)

"When anyone gets a vaccine, they know without a doubt that it has been used for long-term success. (Syracuse)

"Records kept by doctors should show shots given and patient's medical history." (Syracuse)

"I would like to see a slower, safer (none or minimal preservatives) vaccine and schedule." (Syracuse)

Promoting Education and Awareness

Participants believed that education would help increase understanding of vaccine-preventable disease seriousness, informed decision making, and immunization rates. Many participants suggested promoting education and awareness to be important for both the public (patients and parents) and professionals and

referred to a lack of real knowledge about vaccines. Some participants cited a lack of physician encouragement for informed choice and referred to the related issue of lack of physician time for patient education. Education was desired about potential "risk and benefits of vaccines vs. actually getting the disease," side effects, the importance of preventative measures in general, and the extensive research conducted to ensure vaccine safety.

Protecting Our Homeland
Many participants suggested we need to "take care of home first" before helping other countries. Several participants referred to a need to prevent people with certain diseases or without certain vaccines from entering the U.S., while others suggested a need to protect Americans as they leave and reenter the U.S. Several participants emphasized a need to protect the most vulnerable, from children to the elderly. Some included the protection of military personnel stationed overseas in their definition of "homeland." Participants expressed concerns for bioterrorism, the protection of our military and leaders, and diseases carried by foreign visitors into the U.S.

Protecting the Most Vulnerable
Some participants recognized a need to protect the most vulnerable, from children to senior citizens. One person referred to the vulnerable as "people without a voice that we need to speak for"; another described this population as the weakest and sickest members of society. Some associated this value with a need for research and improving our science in order to determine how to protect the most vulnerable.

Reducing Medical Costs
Some participants who prioritized reducing medical costs associated the value with making vaccines more affordable for the public (individual costs), lowering costs for vaccine production, and even protecting the most vulnerable. Others understood it as reducing overall health care costs by preventing illness and complications.

Table 8. Promoting Education and Awareness, Protecting Our Homeland Quotes

Promoting Education and Awareness

"Education to patients and parents. More education and awareness needed." (St. Louis)

"The more you know the more you are protecting all informed consent." (St. Louis)

"I want to be educated about what I put in my body." (St. Louis)

"Can't get help if I'm not educated. Can't get services. Can't be aware of symptoms too." (Columbus)

"Influx of immigrants makes education important so that everyone can be protected." (Columbus)

"Inequity in that some people are in areas where education is available and others aren't." (Syracuse)

"Risk and benefits of vaccine vs. … getting disease. People … should read and be advised by their doctors."(Syracuse)

Protecting Our Homeland

"We must … secure USA first before we consider other countries." (St. Louis)

"World is so small, we need to make sure USA is vaccinated first … to be safe when visitors come …."(Columbus)

"Bioterrorism is a concern … Could affect military, leaders, etc." (Columbus)

"U.S. is a world leader so [we] should be vigilant, safe, and set example for world." (Syracuse)

Improving Our Science
Some participants prioritized improving our science and emphasized independent research over that of pharmaceutical companies. Others believed improving our science would also help us address vaccine safety and global immunization issues.

Ethics

Ethics was a value generated separately by one of the Syracuse small groups and was not in the original list presented. This value of ethics was associated with trust. Several participants described a general lack of trust in the government and doctors to "tell the truth" and a belief that vaccine research and decision making have been done in an unethical manner. Some participants reiterated a need for open and transparent decision making, honesty, accountability, and ethical oversight. In particular, these participants referred to a need to reduce for-profit vaccine production and financial conflicts of interest with vaccine research, which they believed to interfere with the transparency of the vaccine system.

After being presented in a plenary session, ethics was voted as one of the top four priority values in Syracuse. However, ultimately, the value was determined to be an overarching theme that should permeate the entire spectrum of the NVP and was therefore not chosen as a criterion for selecting priority NVP activity areas. For other values proposed by participants for consideration as a top value but ultimately not voted on as ones that mattered most, see Appendix F.

2. Activity areas of the plan that best fit with top values

The activity areas of the plan that best fit with the top values (from the individual votes in table 6) varied among cities, but several similarities occurred (see table 9 for top activity areas shaded in gray). "Improve monitoring of disease and vaccines" was the only top activity area voted on in all three cities as aligned best with the top values. "Make vaccines affordable and available to everyone," "Maintain high rates of vaccination of children," "Assure there is enough vaccine," and "Improve vaccine safety" were important to participants in two of the three cities. "Improve information offered about vaccines" and "Improve tools for making vaccines" were only prioritized by participants in one city. In all three cities, table groups as well as individual participants voted on the same strong alignments (see Appendix F for table votes).

Table 9. Best Activity-Value Fits (After Individual Vote)

Table shows percentages of individuals in each city who voted for an activity area as one of the four best aligned with the top values (from the individual votes in Table 6).

	St. Louis (n = 77)	Columbus (n = 72)	Syracuse (n = 43)
Make vaccines affordable and available to everyone.	82%	92%	35%
Maintain high rate of vaccination of children.	51%	62%	7%
Improve monitoring of disease and vaccines.	52%	38%	87%
Improve vaccine safety.	65%	22%	63%
Assure there is enough vaccine.	49%	70%	12%
Develop new vaccines.	34%	34%	16%
Improve information offered about vaccines.	39%	7%	63%
Improve tools for making vaccines.	39%	24%	49%
Increase vaccination of adolescents.	18%	18%	14%
Increase vaccination of adults.	23%	18%	16%
Help other countries reduce disease through vaccination.	31%	10%	28%
Assure compensation for those injured by vaccines	17%	6%	9%

The number of participant tables in each city that voted a top activity area had a strong (five on a scale of one to five) alignment with a top value appears in table 10. Only the values and activities that were voted among the top in two to three cities were included, and the strongest alignments are shaded in gray. The strongest activity-value alignments were (1) make vaccines affordable and available to everyone with achieving equity and protecting the most vulnerable, (2) maintain high rate of vaccination of children with achieving equity and protecting the most vulnerable, (3) improve monitoring of disease and vaccines with emphasizing safety and protecting the most vulnerable, (4) improve vaccine safety with emphasizing safety and protecting the most vulnerable, and (5) assure there is enough vaccine with achieving equity and protecting the most vulnerable. Achieving equity, emphasizing safety, and protecting the most vulnerable were the most closely aligned values with the top activity areas.

Table 10. Strength of Activity-Value Alignment

Table shows number of tables in each city that voted a top activity area had a strong alignment with a top value. Only values and activity areas voted among the top in two or three cities were included.

Activity	Value	St. Louis (n = 12)	Columbus (n = 11)	Syracuse (n = 8)
Make vaccines affordable and available to everyone				
	Achieving Equity	11	11	8
	Emphasizing Safety	2		
	Promoting Education and Awareness	3		
	Protecting Our Homeland		11	
	Protecting the Most Vulnerable	10	11	
Maintain high rate of vaccination of children				
	Achieving Equity	8	9	6
	Emphasizing Safety	3		1
	Promoting Education and Awareness	4		1
	Protecting Our Homeland		9	
	Protecting the Most Vulnerable	11	12	
Improve monitoring of disease and vaccines				
	Achieving Equity	1	4	
	Emphasizing Safety	8		7
	Promoting Education and Awareness	6		3
	Protecting Our Homeland		7	
	Protecting the Most Vulnerable	5	9	
Improve vaccine safety				
	Achieving Equity	5	2	1
	Emphasizing Safety	10		7
	Promoting Education and Awareness	3		
	Protecting Our Homeland		6	
	Protecting the Most Vulnerable	8	7	
Assure there is enough vaccine				
	Achieving Equity	9	11	7
	Emphasizing Safety	1		
	Promoting Education and Awareness	3		
	Protecting Our Homeland		11	
	Protecting the Most Vulnerable	10	11	

Comments

Reflections on the top best activity-value fits recorded by small-group and plenary group note takers are below.

Make Vaccines Affordable and Available to Everyone

Make vaccines affordable and available to everyone was in the top five alignments of the majority of participants. Some participants believed age did not matter if equity was truly obtained. For these participants, vaccination of all population groups (adults, children, and adolescents) was favored over the concept of "targeting activities to certain audiences" to achieve equity. However, others emphasized vulnerable populations for achieving equity. For some, equity was associated with improving vaccination rates, disease monitoring, supply, vaccine information, and tools to make vaccines. Other participants believed that making vaccines affordable and available to everyone would enable the achievement of other activities, such as maintaining a high rate of vaccination of children.

Maintain High Rate of Vaccination of Children

Some participants prioritized maintaining a high rate of vaccination of children and described children as a precious resource that needs to be "taken care of so they too can pursue research careers and develop new vaccines." Those participants who chose not to select the activity did so because they feel that the current vaccine program already covers children very adequately.

Improve Monitoring of Disease and Vaccines

Participants associated improving monitoring of disease and vaccines with the values of achieving equity, emphasizing safety, improving our science, helping other countries, and protecting the most vulnerable. Some participants suggested that, without monitoring, there is no way to know what diseases and population groups to target. Others believed that proper monitoring of diseases would ensure timely dissemination of alerts about disease outbreaks. Some participants indicated that improving monitoring of diseases and vaccines allows for ethical, more educated decisions on which vaccines have adverse effects.

Improve Vaccine Safety

Safety was discussed in terms of a need for precautionary measures for "when vaccines raise threat of harm to humans or the environment, even if cause and effect relationships are not scientifically proven." Some areas of divergence occurred with improving vaccine safety. Some participants believed that safety is already being accomplished. Other participants saw improving vaccine safety as a priority and necessary for achieving equity, although participants did not rate the activity as a strong fit with the value.

Assure There Is Enough Vaccine

There was some disagreement on assuring there is enough vaccine. Some participants described developing new vaccines as more important than assuring that there is enough vaccine, since, without new vaccines, there is no need to assure supply. Others believed this activity to be covered by other activities.

Develop New Vaccines

Some participants described the U.S. as a progressive country that should always move forward to "new and better" so that they can better protect their people. They described the emergence of new diseases (including HIV) that need vaccines, a need to "keep on top of research" to generate new information and ideas in these new diseases, and a need to be prepared. Developing new vaccines was discussed to help the vulnerable and "those who were not previously helped." Syracuse participants asked for the development of "new vaccines to replace ones we don't like" to help with safety.

Improve Information Offered About Vaccines

Some participants believed this activity also goes hand-in-hand with vaccine safety. Several participants discussed the possible association of education with increasing trust and vaccination rates. Participants

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associated education with improved monitoring, safety, and understanding of vaccines. However, some participants cautioned that "the more information people have . . . can actually make it harder to understand."

Improve Tools for making Vaccines
Participants who voted for improving tools for making vaccines believed tools would make vaccines more readily available and cheaper. They associated the activity with equity, improving science, and emphasizing safety. Others who did not vote for the area described this activity as a part of improving vaccine safety.

3. Priority areas with new money scenario (Columbus only)

A third activity was created to assess prioritization for a new money scenario but was only completed in Columbus due to time constraints. Columbus participants were told they can assume that the level of resources for the NVP will be increasing over what they are now. They were then asked to consider the following question: "If there was increased funding, which three areas would you like to see given priority for additional funding?" An individual vote was conducted.

In plenary session, the results of the vote were presented and compared to the strength of alignment arrived at earlier. Three of the areas remained at the top: (1) make vaccines affordable and available, (2) develop new vaccines, and (3) assure enough vaccines. Developing new vaccines rose in priority and maintaining a high rate of vaccination of children dropped in priority, since participants felt that high rates were already being achieved and new money could go to other places.

4. Insights from dialogue

Participants were asked to discuss insights from the dialogue, and small-group note takers recorded the discussion on work sheets. The top participant insights from the dialogue were related to the open-mindedness required for dialogue amongst diverse participants and the resulting increased knowledge, a need for more education, the importance of trust in the vaccine system, and a surprise in the diversity of dialogue participants.

Open-mindedness and Increased Knowledge
The majority of insights from participants in all three cities were related to their enhanced knowledge and learning that took place from the presentations as well as the interaction with other participants of diverse backgrounds during dialogue. It was frequently cited that open-mindedness helped facilitate the education process that occurred during the dialogue. Specifically, participants learned about vaccine manufacture and safety, the recommended vaccine schedule, international travel requirements, and vaccine accomplishments such as disease eradication. Many participants mentioned that they learned about the U.S. vaccine system and were amazed by its complexity.

More Education
The second most frequently cited insight from the dialogue across all three cities was related to a need for education. Some participants indicated a general lack of vaccine awareness among the general public, but specific education needs related to side effects and targeting seniors were recorded.

Trust
The importance of trust was also reiterated. Distrust of the Food and Drug Administration (FDA) and research agenda by pharmaceutical companies in particular were cited.

Diversity of Participants
Following the dialogue, participants were also surprised at the diversity of participants (see Appendix A for further discussion on diversity).

See table 11 for participant quotes captured in plenary- and small-group notes related to the top four insights. See Appendix F for additional participant insight categories from the dialogue.

Table 11. Important Insight Quotes

Open-mindedness and increased knowledge

"Today reinforces how much the public must be involved in decisions; this should not be a top-down decision." (St. Louis)

"Different opinions … helped everyone develop their ideas; different demographics helped the decisions be made." (St. Louis)

"Enlightening to see all things that go into the process and the trade-offs decision makers need to see." (Columbus)

"Opened my mind to why we need to think of new vaccines and the importance of monitoring to save money." (Columbus)

"Public values … driving decisions and processes. Redefines [our] perspective on the decision-making process." (Syracuse)

"Energized by the process. Getting public input is really important. The hope is they will listen." (Syracuse)

More education

"Education's the key." (St. Louis)

"Government needs to dispense more information to more people." (St. Louis)

"People are unaware of vaccine issues and which ones are available." (Columbus)

"Get behind education and vaccines as there is so much misinformation." (Syracuse)

"Individuals have to advocate and seek their own information rather than trusting a doctor on blind faith." (Syracuse)

Trust

"Government needs to regain trust of the public." (Columbus)

"Need to trust the science—who does it, is it company funded, is science repressed selectively—and give funding not tied to financial gain." (Syracuse)

"The trust issue … it's very tough for mistakes to be admitted, as the consequences can be so high." (Syracuse)

Diversity of participants

"Amazing all the different views considering the same questions … good discussion." (Columbus)

"Like diversity of ideas and respectful debate." (Syracuse)

5. Messages for plan decision makers

The top messages for plan decision makers were related to improving education and dissemination of education materials, increasing trust, ensuring safety, and making vaccines more affordable and available.

Better Dissemination Plan for Education
The majority of messages for plan decision makers were related to the need for a better dissemination plan for educational messages. Some participants described the target audience as global and described a need to educate everyone. Minority populations, expectant mothers, and parents were audiences cited in most need for education. Several participants believed education required diverse communication methods, including continued public dialogues and education through doctor visits, schools, and community centers. Participants desired education about new vaccines on the horizon, vaccine requirements, affordability, and availability.

Increase Trust
Several participants also expressed a need to increase the public's trust in the government, in particular the FDA, and pharmaceutical companies. Trust was associated with assuring fairness in the vaccine system, assuming responsibility, and truthful or unbiased reporting and messaging.

Safety
Some participants were particularly concerned with the safety of children and the elderly. Some discussion suggested a close link between being well informed and safety.

Affordable, Available Vaccines
Affordability and availability of vaccines was also a reoccurring theme throughout the dialogue in all three cities.

See table 12 for specific messages captured in plenary- and small-group notes. See Appendix F for additional message categories from the dialogue.

Table 12. Messages for Decision Makers

Better dissemination plan for education

"Make sure the doctors have all this information … and are passing [it] … on to the patients." (St. Louis)

"Companies that make vaccines should make more information available in laymen's terms." (St. Louis)

"Keep us better informed so that we may act proactively." (Columbus)

"Doctors should share information with their patients about the vaccines." (Syracuse)

Increase trust

"Trust is needed in knowing policy makers are advocating for constituents and not biased interests." (St. Louis)

"The vaccine program (industry) has a trust issue, and it needs to be discussed." (Syracuse)

"Better information on new vaccines, we want the truth!" (Syracuse)

Safety

"If we increase safety and supply, immunization will go up." (St. Louis)

"We want to know the ingredients so we know whether we're allergic to it or not." (St. Louis)

"Please consider alternative vaccination schedules for individuals with autoimmune deficiencies (autism)." (St. Louis)

"Ingredients in vaccines [need to be] readily available and be able to be understood by everyone." (Syracuse)

Affordable, available vaccines

"Government should pay for prevention." (St. Louis)

"Vaccination plan will always be flawed as long as there is money involved/somebody making a profit from it." (St. Louis)

"Think global. Make vaccines affordable to everyone." (Columbus)

"Find better ways to make better, cheaper vaccines for everyone." (Columbus)

"Make vaccines available to everyone." (Syracuse)

Conclusions and Recommendations

Key findings from these three public engagement sessions can inform vaccine planning efforts and the revision of the NVP. Although findings varied among cities and are not fully representative of the general public, participants offered some clear advice about which values and priorities they would like to see reflected in the government's decision making in renewing the plan.

Based on the strength of the alignment of these proposed areas of activity to the participants' most important values, citizens in at least two of the three cities judged the following to be their top priorities for action:
1. Improve monitoring of disease and vaccines
2. Make vaccines affordable and available to everyone
3. Maintain high rates of vaccination of children
4. Assure there is enough vaccine
5. Improve vaccine safety

In making these choices, citizens reflected core public values centered on achieving equity, protecting the homeland, protecting the most vulnerable, having more education and awareness, and being concerned for safety.

Although challenging, the process was completed by citizens who generally found the opportunity to participate rewarding and much appreciated. The process led to a more nuanced understanding and appreciation for what policy makers go through and the trade-offs they wrestle with in their decision making.

What matters most to the public about vaccines are post-licensure improvements in their availability and use, especially for children. The importance of public education and trust in the government vaccine system was also a key insight from the dialogue and key message for decision makers. Application of these dialogue findings to the revised NVP and continuing the dialogue with citizens in the future are steps that decision makers can take to help build this trust, enhance the knowledge that citizens desire, and increase participatory policy making in government.

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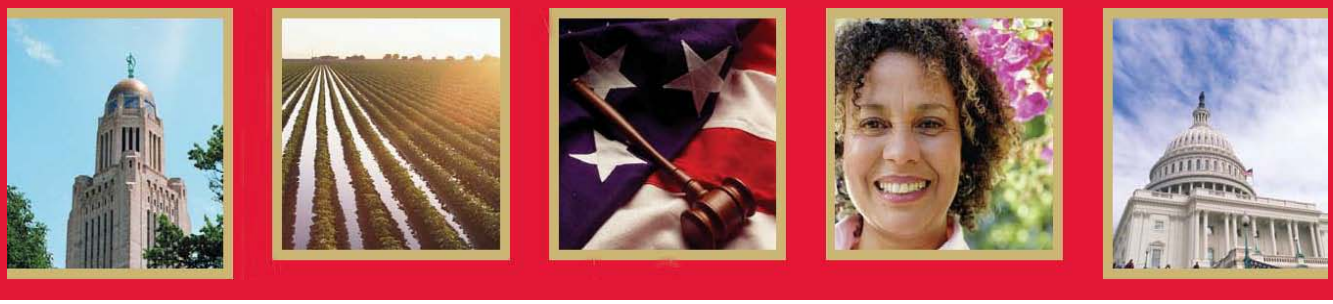
Appendix A. Evaluation Report



Evaluation of a Deliberative Process to Obtain Citizen Input for the Draft Strategic National Vaccine Plan

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Executive Summary

The Deliberative Process to Obtain Public Input for the Draft Strategic National Vaccine Plan occurred in March and April 2009. Public meetings were held in three locations – St. Louis Missouri, Columbus Ohio, and Syracuse New York. Each meeting followed a similar format: 1) A morning presentation of essential information about the U.S. vaccine system, followed by a question and answer session with the participants, 2) introduction of participants to values underlying the U.S. vaccine system with an opportunity to discuss and define the most and least important values, 3) presentation of background information on 12 areas of activity in the U.S. national vaccine program, 4) small group activities in which participants matched their most important values to 12 areas of vaccine activity, and 5) another small group activity in which participants allocated additional funding to national vaccine programs. Throughout the day, participants had opportunities to discuss and decide on the top values they thought should influence national vaccine program activities.

The evaluation included five major components: 1) a pre/post survey to assess changes in knowledge and opinions about social values and priority areas, 2) a post process survey to assess quality of the process, anticipated use of the input, and reasons for participating, 3) comparison of demographic characteristics of participants with census data to assess diversity of participation, 4) post process focus groups with citizens to supplement information about process quality, recruitment efforts, participant knowledge, and expectations about use of the public input, and 5) individual interviews and a focus group with project sponsors and facilitators to understand the project and capture lessons learned. Results of the evaluation include the following findings:

The process was generally successful in attracting citizens to participate in three deliberation days held across the country. Two of the three sites included approximately 100 participants. One site – Syracuse - fell short of this goal, but included enough citizens to engage in the process including doing small group work. Likely reasons for lower participation in the one site include the lack of a stipend paid to participants and selective recruitment efforts. Citizens were motivated to participate by interest in the subject, a desire to learn more about the topic, a feeling of responsibility to contribute to an important public policy issue, and payment for their time.

The process was successful at attracting participants from diverse backgrounds and perspectives. While there were certain groups underrepresented in the meetings (e.g., males) and the characteristics of participants did not exactly match the populations of the participating communities, there appeared to be enough diversity in backgrounds and perspectives to result in meaningfully dialogue and exploration of different sides of issues. Evaluation results found differences in perspectives across demographic groups and meeting locations, thereby reinforcing the need to include diverse representation in public engagement processes to obtain multiple points of view.

The process was successful in improving the knowledge of participants so they could engage in informed discussions about national vaccine policy. The presentation of information and the opportunity to engage in dialogue about the topic resulted in participants' increasing their understanding of critical information about vaccines and vaccine policy. Knowledge increased for all groups regardless of education, income, race/ethnicity, age, gender and geographic location. The process did not, however, result in the same level of knowledge for all participants. In fact the range in understanding the topic was greater after the meetings than before the meetings. To create a more level playing field in which all citizens have an equivalent understanding of the topic, it is recommended that presentations be tailored more to persons of lower educational background and socio-economic status.

The evaluation revealed that citizens changed their perspectives and opinions as a result of the deliberative process. By becoming better informed about the topic areas and engaging in discussions about issues related to vaccine policy, participant views about priority areas and social values underlying the priority areas changed significantly from the pre-test to the post-test. This result indicates that citizen deliberations provide a qualitatively different type and level of input from alternative methods such as public polling or surveys. Contrary to expectations, we did not find the process to result in increased agreement among participants about priority areas and social values.

The process was perceived to be of high quality by citizens and evaluators. We believe this was true in large part to the level of planning of project organizers and facilitators prior to the meetings. Participants rated the process high on a number of dimensions. For example, citizens and stakeholders thought participants felt comfortable talking in the meeting, the discussion was fair to all participants, and the process helped them understand the types of trade-offs involved in developing priorities for national vaccine policy. Satisfaction with the process was consistent across race, ethnicity, age, gender, and income, and family status, indicating the process did not favor one group over another. However, there were differences in satisfaction across the meeting locations, with Syracuse participants being less satisfied with the process. Citizens also anticipated their input would be given serious consideration by decision makers. We recommend developing a feedback process to inform citizens at a later date about how their contributions were used in policy development.

The evaluation included documentation of lessons learned through conducting the deliberative process. Some of these lessons include 1) identifying the purpose and use of public input helps focus the process, 2) creating a common understanding of terms and definitions is important, particularly the values underlying the U.S. vaccine system, 3) attention to detail is important to achieving good outcomes, 4) compensation for citizens appears to increase participation and diversity of participants, and 5) presentation materials need to be tailored to increase comprehension among individuals with varying levels of education and socioeconomic status.

Chapter 1: Introduction

This evaluation examined a process for engaging the public in discussions about priorities for the United States national vaccine plan and explored the opportunities and challenges related to consideration of citizen input by decision makers. The evaluation of this project is important from three perspectives. First, the results will aid the public health field by contributing to the question of whether obtaining citizen and stakeholder input adds value to important public health decisions. Second, the evaluation results may be useful for persons who study public engagement processes; the evaluation is a case study of one type of citizen deliberation process applied to a public health topic, resulting in lessons for other citizen participation efforts. Third, the evaluation may be instructive for persons interested in the mechanics of evaluating public engagement processes.

The Public Engagement Process

The National Vaccine Plan was last updated in 1994. In modifying this plan in 2009/2010, there was a desire by federal agencies to obtain input from citizens in addition to experts and other stakeholders. For the public engagement process, a core planning team was created composed primarily of federal level conveners, the head facilitator, and Oak Ridge Institute for Science and Education (ORISE), who convened regular meetings via teleconference prior to the first engagement forum in St. Louis on March 14. The planning meetings primarily focused on design of the engagement exercises, recruitment of participants, and development of the evaluation survey vis-à-vis the objectives of the project. The actual process design was generated primarily by Dr. Roger Bernier of the Centers for Disease Control and Prevention and Jacquie Dale of One World Inc.—the head facilitator. Among this core team of planners, there was a division of labor between ORISE personnel—who largely concentrated on providing project administration and logistical support, and the facilitator and CDC/HHS personnel—who concentrated on designing the engagement activities. This division of labor among the core planning team would prove helpful because it allowed team members to concentrate on the specific areas for which they were accountable. Materials and processes for the public engagement events were pretested with ORISE employees who were not health care workers on February 18, 2009. The final process design was then finalized prior to the three deliberations in St. Louis, MO; Columbus, OH; and Syracuse, NY.

The core activities for the engagement process included the following basic components:

1. A morning presentation of essential information about the U.S. vaccine system, followed by a question and answer session with the participants.

2. A morning activity in which participants are introduced to the concept of underlying values behind the U.S. vaccine system, and asked to discuss and identify the values most and least important to them.
3. An afternoon presentation on the 12 areas of activity in the U.S. national vaccine program plan.
4. An afternoon activity in which participants align the top five values identified in the morning with each of the 12 areas of activity by allocating a point value to each top value per activity. One point was assigned to values that had a weak alignment to the program activities; three points were assigned to those values with medium alignment to the program activities; and five points were assigned to those values with the strongest alignment to the 12 areas of activity.
5. A final activity in which participants are asked to indentify which 3 areas of the national vaccine program they would prefer to prioritize if new funding was made available.

After each of the activities, there were a series of live electronic voting sessions in which participants were asked to vote for or identify the outcomes following their small group discussions. Some of the voting was conducted by individual participants and other votes were tabulated by group or table. Voting was followed by large group discussions led by the head facilitator in which tables had the opportunity to report back results and discuss perspectives. Throughout the process, expert resource people from the CDC/HHS or state representatives were encouraged to observe and roam among participants to answer questions. All activities were preceded and followed by the pre and post evaluation surveys.

Local conveners were primarily responsible for promotion and recruitment of participants to the engagement forums, recruitment of small group facilitators, securing meeting spaces, and arranging for catering and other administrative details. Working with the core planning team—particularly ORISE—the local conveners identified training dates for small group facilitators within the week prior to the actual event.

Following the St. Louis forum, the core planning team made three significant changes to the process activities. First, changes to the morning values activity were made in an attempt to better define the meaning of the values for participants. Slight changes were made to the definitions of some values, as well as to how they were presented on the values cards provided to participants. Second, the number of values and activities participants were asked to select was cut from 5 to 4, in the interest of time and ease for participants. And third, during the question and answer period after the morning's presentation, resource people went table to table answering questions, rather than one person at the podium answering questions. This allowed participants to have more of their questions answered in the allotted amount of time.

The agenda was similar in the three cities. St. Louis participants' task was slightly more difficult and took longer because they were asked to select their top 5 priorities rather

than their top 4. In Columbus, the process included a scenario in which participants were asked how they would allocate new money to vaccine activities; this activity was not included in the St. Louis or Syracuse deliberations. The recruiting process differed in Syracuse in two ways: the only medical and public health professionals screened out were physicians and nurses, and gifts were provided instead of monetary compensation. The number of participants in Syracuse was about half that in St. Louis and Columbus.

Evaluation Questions

The evaluation examined the following questions:

1. Participation and recruitment questions:
    a. How successful was the process in attracting citizens to deliberations in three meeting locations: St. Louis Missouri, Columbus Ohio, and Syracuse New York?
    b. How successful was the process in attracting citizens with diverse backgrounds and perspectives?
    c. What motivated citizens to participate in the process and what could have improved recruitment?

2. Process quality
    a. How successful was the process in providing a sufficient level of citizen knowledge about vaccine policy so they could engage in informed discussions?
    b. How did the process affect citizen perceptions about vaccine goals and values underlying those goals?
    c. To what extent did the process result in a balanced, honest, and reasoned discussion of the issues and what would have improved the process?

3. Perceptions about the product
    a. What were citizen perceptions about how the input would be used?
    b. What are the lessons learned that can be used to improve future public engagement processes?

Chapter 2: Evaluation Methods

This study employed a mixed method design using quantitative and qualitative information. The University of Nebraska-Lincoln Institutional Review Board approved the evaluation design and all participants were asked to complete an approved informed consent form to participate in the evaluation. There were six major methodological components:

1. Conduct a pre/post survey of meeting participants in three citizen meeting locations to assess change in knowledge, goals and values.
2. Obtain demographic information about participants.
3. Conduct a post meeting survey to obtain citizen perceptions about the process
4. Conduct a post meeting focus group to gain deeper understanding about citizen perceptions of process and outcomes from the meeting.
5. Conduct interviews with conference sponsors and facilitators to understand the process, the rationale for the process, and lessons learned from conducting the process.
6. Conduct an analysis of deliberation participant demographic characteristics compared to characteristics of the site's general population.

The pre and post-surveys were conducted through a combination of electronic polling and paper and pencil surveys. The pre-survey had two sets of questions: multiple-choice questions assessing knowledge about vaccines and a section asking opinions about public health priorities, vaccine goals, and values. The post-survey included these two sets of questions and a set of questions about the quality, fairness and effectiveness of the deliberative process and recruitment process. Questions were pre-tested and modified to improve comprehension of questions and answers. To help reduce response-order bias, three versions of each survey were administered with the order of questions randomly varied in the opinion-questions sections.

For evaluation questions administered through a paper and pencil survey, citizens received pre-tests at the beginning of each meeting. Organizers asked them to find a seat and complete the survey immediately. At the end of the meeting, participants had about 15 minutes to complete the paper and pencil post-test. Some of the demographic information for one meeting was collected through electronic voting, and the voting occurred in the first half hour of the meeting. We were able to link the information from the electronic voting to the written surveys so we could compare information by individual. For the pre-post surveys, there was a 15.4% attrition rate (see Table 1). Results from the pre-post survey included the 208 participants who completed both the pre-survey and the post-survey.

Table 1

Number of Pre-tests and Post-tests Completed and Attrition Rate

City	Pretest Number	Posttest Number	Attrition Number	Attrition Rate
OVERALL	246	208	38	15.4%
St. Louis, MO	94	86	8	8.5%
Columbus, OH	98	78	20	20.4%
Syracuse, NY	54	44	10	18.5%

Citizens were asked to volunteer to stay after the meeting and participate in a focus group. Respondents self-selected to join each focus group. The focus group questions for citizens included how they perceived the information presented at the meeting; the quality of the participation; aspects of the process that influenced their opinions; their satisfaction with the process; how the process could have been enhanced; and how they thought policy makers would consider their input. Citizens were asked to share their perception of how representative of the general public the participants at the meeting were, how they found out about the meeting, and why they participated. Interviews with event organizers and facilitators were conducted by telephone. Evaluators supplemented survey and interview results with direct observation of the meetings.

Analyses

The evaluation logic model can be found in Appendix I. Quantitative data from the pre/post surveys was analyzed using the software package SPSS v17. Atlas.ti, a qualitative analysis software package, was used to organize information from audio tapes and detailed notes from focus groups, interviews and observations. Triangulation with multiple coders and data sources served as a validation strategy. The qualitative data was intended to provide depth and explanation for quantitative findings.

To assess the extent which the process was successful in attracting citizens with a broad diversity of perspectives, we examined the demographic characteristics of meeting participants and compared them to the demographic characteristics of the general population in the community where the meeting was held. We used chi-square tests to determine statistical significance related to demographic differences. Quantitative analysis was supplemented with direct observations of the diversity of perspective and citizen perceptions about the diversity of participants.

To assess the knowledge of participants related to information about vaccine policy, we compared change in knowledge on the pre and post-survey. A two way Analysis of Variance (ANOVA) was used to determine statistical significance between pre and post-scores including significance testing for each knowledge question. Direct observation of

the level of discussion among citizen deliberators by the evaluators and vaccine experts supplemented the quantitative analysis. We also assessed the participants' perceptions about their level of knowledge and their ability to engage in informed discussion through survey questions and focus group responses. We examined how knowledge and change in knowledge were related to demographic characteristics of participants within and across sites.

To assess the process we relied on direct observation by evaluators, facilitators and meeting organizers. We gauged citizen perceptions of the process through standard ratings on the post--survey as well as qualitative information obtained through the focus groups. To assess how the process affected the goals, values and priorities of the citizen participants, we relied on the pre/post survey. Two way Multivariate Analysis of Variance (MANOVA) was used to test for statistically significant differences between pre and post-ratings. We supplemented the quantitative results with participant perceptions about how and why their opinions may have changed. We examined how values, goals and priorities are related to citizen demographic characteristics, to the level of knowledge of citizens and to the satisfaction of citizens with the process within and across sites.

Chapter 3: Evaluation Results – Recruitment and Participation

Summary of Findings

- The process was successful at attracting citizens to deliberations; although in one site, only about half the desired number of citizens participated
- Major motivators for participating include interest in the subject, the desire to gain knowledge about the topic, and a feeling of responsibility to contribute to an important public policy issue
- The process was successful at attracting participants of diverse backgrounds and interests, although the demographic characteristics of participants did not mirror those of the communities within which the meetings were held.
- The evaluation results suggest public engagement processes could benefit from a standardized recruitment process across sites that includes stipends as an incentive for participation and employs multiple methods targeted toward diverse groups.
- Providing incentives, such as stipends or gifts, only after completing the process would likely reduce attrition.

Reasons for Participation

The goal of the public engagement process was to recruit a sufficiently large number of citizens to participate in each meeting and to have citizens represent a diversity of perspectives and backgrounds. A "rule of thumb" goal for the citizen deliberations was to attract 100 participants at each of the three sites; organizers believed that a process having large numbers of citizen participants would be perceived as more credible and generalizable by decision makers. In addition, facilitators wanted a sufficient number of citizens to allow small group deliberations. Evaluator observations and findings from the focus groups and interviews indicate the process was successful at recruiting and attracting citizens to participate in the deliberative process. Each citizen meeting included enough citizens to have multiple small group discussions. As shown in Table 2, two of the three meetings attracted approximately 100 citizen participants.

Table 2
Number of Citizen Participants by Community

City	Number of Participants
St. Louis, Missouri	97
Columbus, Ohio	107
Syracuse, New York	55*
Total	259

* Estimated from return of pre and post surveys

Attrition of participants was an issue. Although exact numbers of participants who left early were not recorded at each meeting, one conference organizer estimated that about 15% of citizens left the meeting before the process was concluded. There is support for this attrition rate from the completion of pre and post surveys; 15.4% of individuals who completed the pre-survey in the morning did not complete the post-survey at the end of the process (see Table 1). One method to reduce attrition would be to require participants to complete the entire deliberation process before they receive their incentive for participating, although there may be ethical issues with mandating completion if the deliberation is conducted as part of a research project.

St. Louis and Columbus participants were paid a $50 stipend to attend; Syracuse provided gifts but did not offer cash incentives. The stipends and gifts were provided to participants whenever the elected to leave the meeting; participants were not required to attend the entire meeting to receive their incentive. Recruitment was done through flyers and emails to community groups, schools, advocacy and faith-based groups. Word of mouth was also relied upon in all cities to draw participants. Some local organizers thought if they had more time to recruit, they could have attracted greater numbers of participants. Participants were asked in focus groups and on evaluation surveys what made them decide to attend the event and how they learned about it.

Compensation was a reason given for deciding to attend by about a fifth of the participants in St. Louis and Columbus, usually in combination with a statement about the educational benefit of the event. For example, “Free knowledge with a small payment for my time,” and “Curiosity and compensation”. A review of evaluation survey comments revealed that individuals citing compensation as a draw tended to be younger than the overall sample. The impact of compensation was discussed in focus groups after the event in St. Louis and Columbus. Generally, compensation was seen as a valid way to draw diverse participants to the event: “I’m sure originally some people came for the money, but once the meeting got started, it came out we all had different opinions about it and we all feel differently about it [vaccination issues].” One organizer/key stakeholder commented: “I was pleasantly surprised, even with people who said they were there only for the 50 dollars, a lot of them got into the issues and they really did want to talk about the issues and dialogue with their group.”

Other reasons cited for attendance related to civic responsibility (“Civic duty” and “Social responsibility”), previous experience with public engagement events (“I attended another meeting, heard the event needed more people, am interested in the topic, and wanted the event to succeed”), curiosity (“Some thing to do today”) and an interest in

the topic ("This is a topic I consider to be very important"). A number of participants attended because they were personally affected by vaccine issues, particularly in Syracuse, for example: "I have a child with autism. He was injured by vaccines" and "It is an important topic to me. I have a 1yr old son and want to better understand issues and bring up problems I have with the current system."

The majority of participants from Syracuse (82%) learned about the event through either the local University or FOCUS (the local coordinating partner). St. Louis participants heard about the event through friends and materials distributed through FOCUS St. Louis, the Public Health Department and a Father's Support Group. St. Louis participants who said they heard through friends, word of mouth or the Support Group were more likely to identify themselves as African American than other participants. Columbus participants identified a diverse set of recruiting strategies as influencing their decision to attend, including flyers (provided by or left at community agencies), emails, friends, family and co-workers.

Focus group participants were asked about their expectations coming into the day. The general theme arising from all groups was that participants came with the expectation they would learn something new about vaccines and vaccination policy. Many of them were interested in gaining information to increase their understanding of personal situations. It should be noted that these events took place in proximity to National Autism Month, which may have influenced attendance and heightened awareness of vaccination issues for participants.

> "I have 2 grandchildren who are autistic and actually have 4 grandchildren with hyperkinetic conditions. I was not sure if it was environmental versus a vaccination issue. I wanted to learn the effects for myself and how decisions are made."

"I am a special education teacher and I get lots of questions from the parents all the time about whether or not vaccines caused or contributed to their child's issues."

Diversity of Participants

A goal of the project was to attract a diversity of participants, both in terms of demographic characteristics and perspectives. It was not necessarily the goal to have the participants match the exact demographics of the United States or of the communities in which the meetings were held, but rather to have enough diversity to hear multiple perspectives from different sectors of the population. In this sense, it appears the process was successful. Participants represented a diverse mixture of demographic characteristics and perspectives. For participants who completed the post-survey, the demographic information indicates diversity within the sample in age, gender, race/ethnicity, education, and income, although participants were not exactly representative of the general population in the three communities.

Figure 1 shows the proportion of citizen participants of each gender for the three meetings. Participants were predominantly female. St. Louis had the greatest proportion of male participants (41.9%) compared to the two other sites; approximately 25% of participants in the Columbus and Syracuse meetings were males.

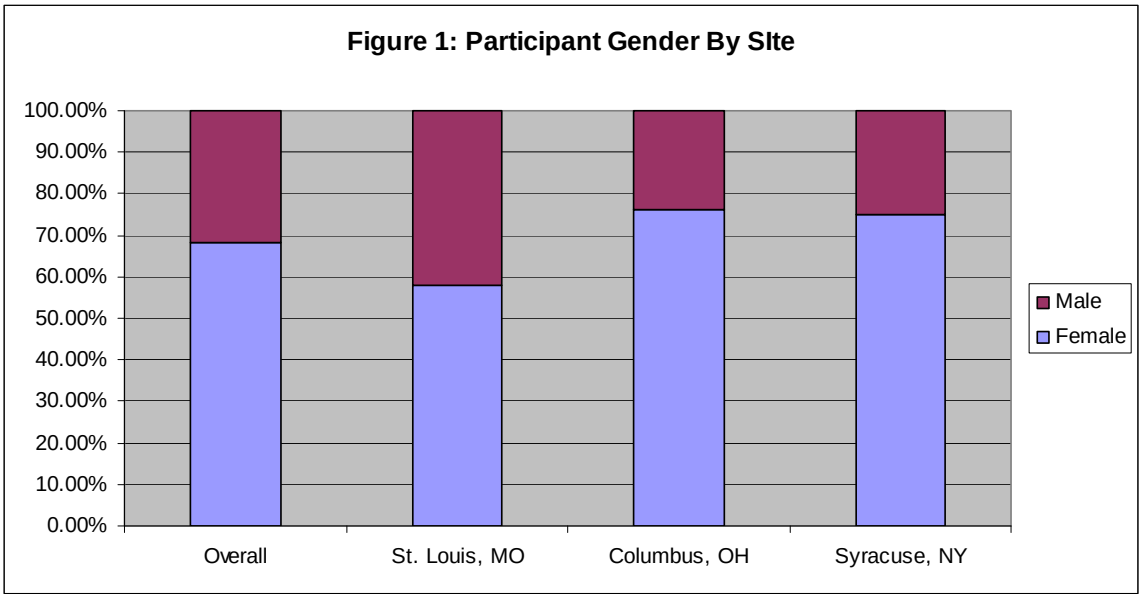


Table 3 shows the ages of participants across the three meeting sites. Participants represented a cross section of ages, although a majority of participants were 45 years of age or older. There were no significant differences across the three meeting sites with respect to age of participants.

Table3
Age of Citizen Participants by Meeting Location

Ages	Overall	St. Louis	Columbus	Syracuse
18-24	10.0% (n=21)	12.4% (n=11)	6.5% (n=5)	11.6% (n=5)
25-34	15.3% (n=32)	10.1% (n=9)	23.4% (n=18)	11.6% (n=5)
35-44	15.8% (n=33)	13.5% (n=12)	19.5% (n=15)	14.0% (n=6)
45-54	23.0% (n=48)	23.6% (n=21)	20.8% (n=16)	25.6% (n=11)
55-64	20.6% (n=43)	22.5% (n=20)	16.9% (n=13)	23.3% (n=10)
65+	15.3% (n=32)	18.0% (n=16)	13.0% (n=10)	14.0% (n=6)
ESTIMATED MEAN AGE	*42.5*	*43.8*	*45.8*	*42.9*

Table 4 compares the race and ethnicity of citizens across the three meeting locations. There was a mix of racial and ethnic diversity across the three sites. Non-Hispanic whites were the largest single group for all three meetings and constituted the majority of participants in Syracuse. There was less racial/ethnic diversity in Syracuse than in the other two meeting locations. Syracuse had a significantly lower proportion of Hispanics and Non-Hispanic Blacks than the other locations.

Table 4
Race/Ethnicity of Citizen Participants by Meeting Location

Race/ Ethnicity	Overall	St. Louis	Columbus	Syracuse
Hispanic White	5.4% (n=11)	3.5% (n=3)	9.3% (n=7)	2.4% (n=1)
Hispanic Black	6.9% (n=14)	9.4% (n=8)	6.7% (n=5)	2.4% (n=1)
Non-Hispanic White	46.5% (n=94)	40.0% (n=34)	41.3% (n=31)	69.0% (n=29)
Non-Hispanic Black	34.7% (n=70)	41.2% (n=35)	36.0% (n=27)	19.0% (n=8)
Asian	1.0% (n=2)	0% (n=0)	2.7% (n=2)	0% (n=0)
Native American	2.5% (n=5)	3.5% (n=3)	1.3% (n=1)	2.4% (n=1)
Other	3.0% (n=6)	2.4% (n=2)	2.7% (n=2)	4.8% (n=2)

Table 5 shows the education level of participants across the three meeting locations. Overall, participants in the three meetings represented diversity in level of education, although the majority in each meeting had at least some college experience. On average, participants in Syracuse had a significantly higher level of education than participants in Columbus or St. Louis. No participant from the Syracuse meeting reported having less than a high school education; nearly 75% of Syracuse participants reported having at least a college degree. This was noted by Syracuse focus group attendees as they expressed concern about that lack of diversity across education levels ("*We all had at least BA degrees and I was concerned about the educational level represented*") and that recruitment had not been extended to rural areas surrounding the city. "*I didn't know if we were covering rural counties; that concerned me*."

Table 5
Education of Citizen Participants by Meeting Location

Education	Overall	St. Louis	Columbus	Syracuse
Less than high school (1)	3.3% (n=7)	5.6% (n=5)	2.6% (n=2)	0% (n=0)
Some high school (2)	9.1% (n=19)	10.1% (n=9)	13.0% (n=10)	0% (n=0)
High school graduate (3)	16.3% (n=34)	18.0% (n=16)	20.8% (n=16)	4.7% (n=2)
Some college (4)	25.8% (n=54)	25.8% (n=23)	28.6% (n=22)	20.9% (n=9)
College graduate (5)	19.1% (n=40)	18.0% (n=16)	19.5% (n=15)	20.9% (n=9)
Some graduate school (6)	7.2% (n=15)	5.6% (n=5)	2.6% (n=2)	18.6% (n=8)
Graduate school graduate (7)	16.2% (n=40)	16.9% (n=15)	13.0% (n=10)	34.9% (n=15)
MEAN	*4.46*	*4.25*	*4.09*	*5.58*

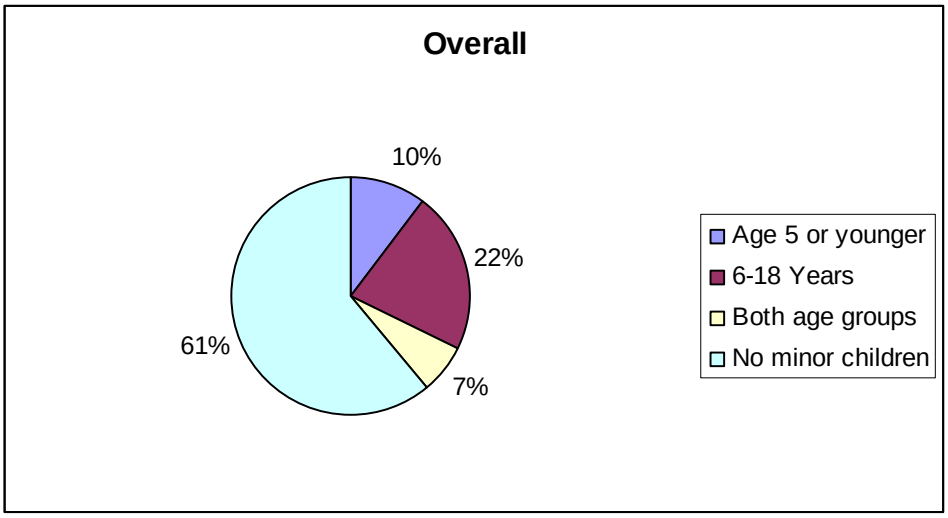
Table 6 shows the self-reported household income for citizens who participated in the three deliberations and completed the survey. Each meeting site included citizens with incomes across the economic spectrum. Syracuse participants were much less likely to have annual incomes $15,000 or less and much more likely to have incomes over $60,000 than participants at either of the other two sites.

Table 6
Annual Household Income of Citizen Participants by Meeting Location

Annual Income	Overall	St. Louis	Columbus	Syracuse
$15,000 or less (1)	37.8% (n=79)	46.3% (n=38)	46.2% (n=36)	12.8% (n=5)
$15,001 - $30,000 (2)	16.7% (n=35)	11.0% (n=9)	23.1% (n=18)	20.5% (n=8)
$30,001 - $60,000 (3)	21.1% (n=44)	22.0% (n=18)	20.5% (n=16)	25.6% (n=10)
$60,001 - $100,000 (4)	12.9% (n=27)	14.6% (n=12)	3.8% (n=3)	30.8% (n=12)
$100,001 or more (5)	4.8% (n=10)	4.9% (n=4)	2.6% (n=2)	10.3% (n=4)
MEAN	*2.25*	*2.20*	*1.89*	*3.05*

Figure 2 shows the percentage of participants reporting they have children at home for each site and across the three sites combined. All three sites included citizens who had children living at home, although the majority of participants at each location had no minor children living at home. Citizens participating in the St. Louis meeting were least likely to have children living at home, while citizens at the Columbus meeting were most likely to have children living at home.

Figure 2
Children Living at Home for Citizen Participants by Meeting Location



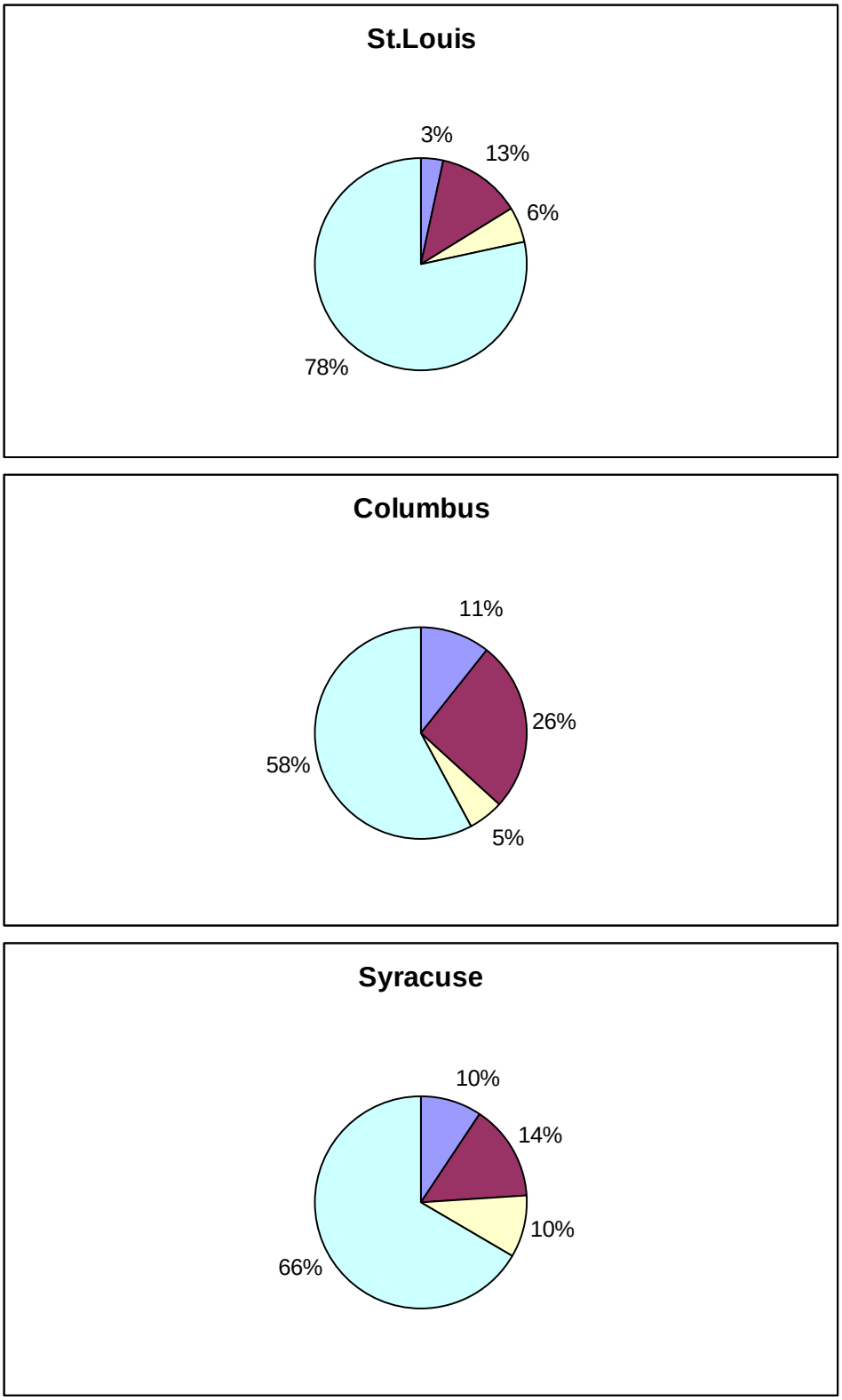

St.Louis
3%
13%
6%
78%
Columbus
11%
26%
58%
5%
Syracuse
10%
14%
10%
66%

Table 7 compares the demographic characteristics of participants in the three meeting locations to the demographic characteristics of the general population in the United States who are ages 18 years and older. In addition, we compared the demographic characteristics of meeting participants with the characteristics of the populations within each of those communities. **Gender:** In relation to the demographic characteristics of the population in general, males were underrepresented and females were overrepresented compared to the U.S. population and to the populations in the community for each meeting site. **Age:** Meeting participants across the three sites were not significantly different in age compared to the national population. The only significant difference for each of the three sites was that 55 – 64 year olds in St. Louis were overrepresented in relation to those in the community. **Race/Ethnicity:** Overall,

Non-Hispanic Blacks and American Indians/Alaskan Natives were overrepresented at the deliberations compared to the U.S. general population; Non-Hispanic Whites and Asians were underrepresented. In relation to community demographics, Hispanics and American Indians/Alaska Natives were overrepresented in St. Louis and Columbus. Non-Hispanic Whites were underrepresented in Columbus. Although participants were less racially and ethnically diverse in Syracuse than in the other two locations, participants tended to reflect the race/ethnic characteristics of the broader Syracuse community. **Education:** Overall, those with some college education and graduate school degrees were overrepresented at the meetings in comparison to the U.S. population over age 25; those with less than a high school education and only a high school diploma were underrepresented. In relation to the demographic characteristics of the each

community, participants with graduate school degrees were overrepresented in Syracuse. **Households with Children:** There were no significant differences between the meeting participants regarding the proportion who had children living at home. In relation to community demographics, households with children under 18 years of age were overrepresented in Columbus.

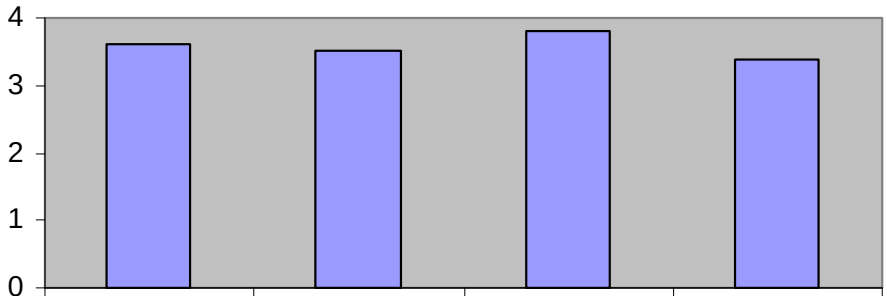
Table 7
Comparison of Participant Demographics to U.S. Demographics

Demographic Variable	Meeting Participants	U.S. Demographics
Gender		
Females	68.4%	50.8%
Males	31.6%	49.2%
Age		
18-24	10.0%	13.1%
25-34	15.3%	17.8%
35-44	15.8%	19.4%
45-54	23.0%	19.2%
55-64	20.6%	14.0%
65+	15.3%	16.6%
Race/Ethnicity		
Hispanic White	5.4%	14.7%
Hispanic Black	6.9%	
Non-Hispanic White	46.5%	66.3%
Non-Hispanic Black	34.7%	12.2%
Asian	1.0%	4.3%
Native American	2.5%	.7%
Other	3.0%	1.9%
Education		
Less than high school	3.3%	6.5%
Some high school	9.1%	9.5%
High school graduate	16.3%	30.0%
Some college	25.8%	19.6%
College graduate	19.1%	24.5%
Some graduate school	7.2%	
Graduate school graduate	19.1%	9.9%
Children at Home		
Yes	31.6%	31.4%
No	68.3%	68.6%

Participants perceived that the meetings attracted citizens from diverse perspectives and backgrounds (see Figure 3). When asked to rate the statement, “Participants at this meeting represented a broad diversity of perspectives,” citizens on average provided a

3.6 rating on a four point scale indicating general agreement. There were differences across the three sites. Participants at the Columbus meeting rated this item significantly higher and participants at Syracuse rated this item significantly lower.

Figure 3: Perceptions about Diversity of Participants



	Overall	St.Louis	Columbus	Syracuse
Mean Rating	3.60	3.52	3.81	3.37

The general impression of focus group participants in all cities was that a diversity of opinion was represented, "It was a really diverse group and everybody at the table wanted to learn something." Some commented that the participants adequately reflected their community, "All walks of life were here." But others expressed concern that some groups may have been underrepresented at the events, including in the make-up of the presenters and organizers of the events:

"I realize that there isn't a lot of diversity on the decision making level. The presenters – the ethnic diversity is not there either. Previous studies have historically given people of color a reason to be suspicious."

Chapter 4: Evaluation Results – Citizen Knowledge

Summary of Findings

- The process was successful at increasing relevant knowledge of participants, so citizens could engage in informed dialogue
- Knowledge increased across equivalently across demographic groups based on education, income, race/ethnicity, age, gender, and geographic location.
- Participants believed they had adequate knowledge to make informed choices about vaccine policy
- The process did not equalize knowledge across groups; for example, persons with higher education levels understood the information better than participants with lower education levels.
- The evaluation findings suggest information presented should be tailored to participants with lower education.

Knowledge of Participants

Citizens were given a nine-item knowledge test at the beginning and end of each deliberation. As indicated in Table 8, average scores for citizen knowledge increased significantly from the pre-test to the post—test ($F(1, 205) = 163.262$, $p < .001$). There were no significant differences in citizen knowledge across the three sites ($F(2, 205) = 2.975$, $p = .053$). However, it should be noted that the knowledge difference between Syracuse and the other two sites approached significance. Participants in the Syracuse meeting had higher scores on the pre-test than the other two sites. This is likely due to the higher level of education of Syracuse participants and that many of them had particular interest in the topic area. There were no significant differences across the three sites in knowledge change ($F(2, 205) = 1.155$, $p = .317$). This indicates the process used in all three locations to inform participants was equivalent and met the objective of increasing knowledge.

Table 8
Change in Participant Knowledge by Meeting Location

Knowledge Scores	Overall (n=208)	St. Louis (n=86)	Columbus (n=78)	Syracuse (n=44)
Pretest Mean (Std Dev)	51.01 (21.63)	49.48 (22.40)	50.28 (20.71)	55.30 (21.63)
Posttest Mean (Std Dev)	71.79 (25.59)	69.12 (26.86)	69.66 (23.12)	80.81 (25.74)

Knowledge by Different Groups

To assess whether the process was more successful at increasing knowledge for some categories of participants than others, we examined change in knowledge by

demographic variables. Table 9 shows pre- and post-test knowledge scores based on education. Perhaps not surprisingly, the higher the education level, the higher the scores on both the pre-test and post-test ($F(1,198) = 133.034$, $p < .001$). Those with less than or some high school scored 16.78 percentage points lower than those with some college or college graduates ($p=.002$). Participants with less than or some high school scored 22.23 percentage points lower than those with some graduate school or graduate school graduates ($p<.001$). One might anticipate that the deliberation process might equalize knowledge across education groups. The results indicate that the level of knowledge change did not differ significantly across groups; persons with lower education had less knowledge about vaccines coming into the meetings, and while their level of knowledge increased as a result of the deliberations, their level of knowledge did not increase at a different rate than those with higher education. Hence, the process was not successful at bringing the level of knowledge of lower educated persons up to the same level of knowledge of higher educated persons after the meeting. In fact, Table 9 shows that the disparity in knowledge actually increased during the course of the meetings. The standard deviation, which is a measure of the range of knowledge scores increased from 21.63 on the pre-test to 25.59 on the post-test (see Table 8 above). To create a meeting environment in which all participants have an equivalent level of knowledge may require presentations and meeting materials geared toward the learning styles and level of comprehension of persons with high school degrees or less than high school degrees. There was also a significant difference in knowledge across income groups, with persons of higher income showing greater levels of knowledge on the pre and post-test. This result may be linked to a relationship between income and level of education; income and level of education are significantly correlated ($r = .510$, $p < .001$).

Table 9
Change in Participant Knowledge by Education

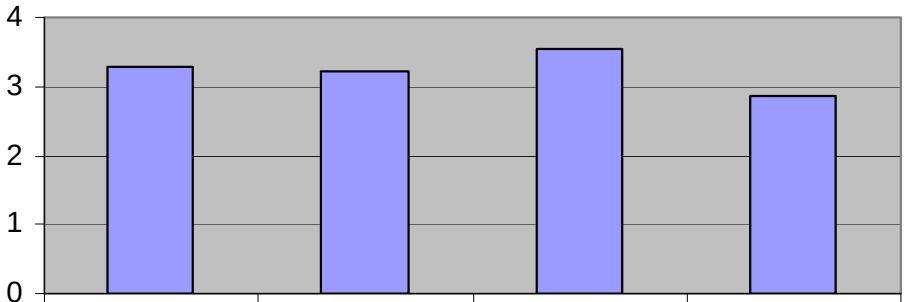
Knowledge Scores	Less than or some high school (n=23)	High school graduate (n=32)	Some college or graduate (n=94)	Some graduate school or graduate (n=53)
Pretest Mean (Std Dev)	38.65 (21.15)	44.44 (21.49)	54.37 (19.10)	56.60 (21.60)
Posttest Mean (Std Dev)	56.52 (23.43)	64.58 (26.54)	74.35 (24.87)	83.02 (15.95)

Perception of Knowledge

To supplement the knowledge test, we assessed the degree to which citizen participants thought they had enough knowledge to understand the issues around vaccines. In response to the statement, "I have enough information right now to have a well-informed opinion," citizens rated this item an average of 3.28 on a scale of 1 – 4 with "4" meaning agree strongly and "1" meaning disagree strongly (see Figure 4). There were significant differences across the three meeting sites ($F(2,189) = 14.961$, $p < .001$). Respondents in Columbus expressed stronger agreement (3.55) than did respondents in

St. Louis (3.23) who, in turn, expressed stronger agreement than did respondents in Syracuse (2.85). There were no significant differences for this item across gender or age groups; however there was a significant difference across education level ($F(36, 525) = 1.468$, $p < .041$). Although performance on the knowledge test items indicated persons with lower levels of education understood the information less, these same participants (those with some high school or a high school degree) rated this item significantly higher than participants with a graduate degree or some graduate school ($p = .018$).

Figure 4: Perceptions of Knowledge by Meeting Location



	Overall	St.Louis	Columbus	Syracuse
Mean Rating	3.28	3.23	3.55	2.85

Columbus focus group participants noted in the focus group that the information presented at the event was appropriate and easy to understand: "I liked the presentations. We weren't talked down to but it wasn't over my head." Focus groups in Syracuse and St. Louis were not as positive about the presentations. They said the information was too complex and presented in a way that did not help participants understand it:

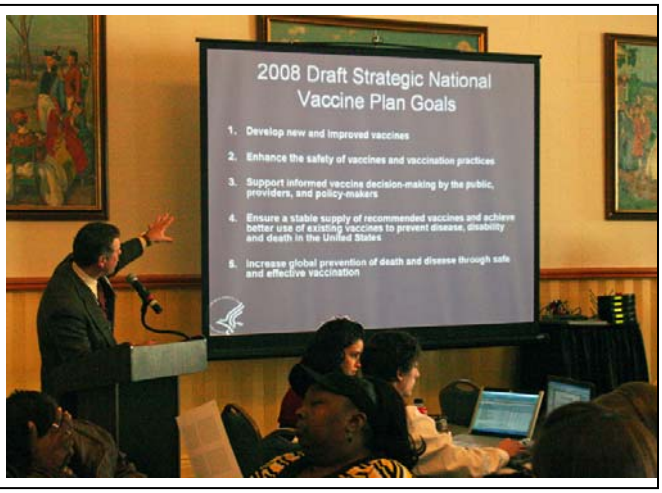
> "We had at least one person in my group who was functionally illiterate and the language level was much too high. It needed to be simpler. It was not appropriate to the audience."

"I lacked a sense of context in the initial presentation."

All focus group participants were asked to suggest additional information that would have assisted them in their dialogues. Several focus group participants said they would have liked more information on the history and process of developing new vaccines and how vaccine development is funded in the United States. They also asked for

information about vaccines that presented concerns rather than just assuming that all vaccines are “lovely and wonderful.”

Most participants appreciated the availability of experts and resource personnel at the events who could answer questions as they arose. They complimented the facilitation and noted that facilitators helped bring participants into the conversation. Generally participants in the focus groups believed that differing opinions were taken into consideration in discussions.



“Even if you didn’t feel certain things, people took into consideration what people had to say.”

“There were a lot of different opinions. It was a good discussion.”

Chapter 5: Evaluation Results – Impact of Deliberations on Beliefs

Summary of Findings

- As a result of the deliberative process, the opinions of participants changed.
- Opinions about values and priority areas varied significantly across the three meeting locations; this evaluation finding reinforces the need to conduct public engagement processes in multiple geographic locations.
- Opinions about values, although not priority groups, varied significantly base on the income, education level and race/ethnicity of participants; this finding reinforces the need to attract diverse demographic groups to deliberative processes in order to obtain a variety of perspectives.

Changes in Beliefs

Survey results indicate some opinions regarding social values and priority areas changed for citizens after they received information and deliberated about vaccines. This change is important in that it indicates that something in the deliberative process actually influences participant thinking and beliefs. Participants reported in focus groups that interactions among participants influenced their opinions.

"It changed my opinions, just from listening to the people who were there."

"I watched my own and others' attitudes change when forced to make choices."

"One woman hated vaccinations but she heard what everyone had to say and she just totally turned around her opinion because of what the people talked about."

Participants were asked to rate 14 social values on a scale from "1" (not at all important) to "4" (very important). Three of these items were worded differently between cities and are separated in Table 10 from the ranked listing of the other 11 items. The results on the evaluation post-survey were consistent with final individual electronic polling. The top four post-survey values were included in the top five electronic polling results; "Protecting our Homeland" was rated high in electronic polling but not as high on the evaluation post survey. As part of the evaluation, we were interested in changes in participant values ratings between the beginning and end of the process. All but four of the social values were rated significantly lower in importance on the post-test compared to the pre-test. One might predict that as a result of the deliberations, citizens would have more agreement in their views; however, as shown by an increase in the standard deviations on 12 of the 14 items, rating of social values became more disparate on the post--test compared to the pre-test. Given that part of the process involved defining the values in small group discussions, it is possible that within a group agreement was reached but that between the small groups common definitions of the values were not shared. Perhaps also the divergence of values reflects the increased variation in understanding of relevant information, discussed in Chapter 4 above.

Table 10
Rating of Social Values Before and After Deliberation Meetings

Social Values	Pre-test Mean (Std Dev)	Post-test Mean (Std Dev)
Achieving Equity	3.69 (.63)	3.73 (.60)
Promoting Education and Awareness	3.74 (.56)	3.66 (.64)
Emphasizing Safety	3.84 (.47)	3.64* (.59)
Protecting the Most Vulnerable	3.77 (.58)	3.64* (.68)
Securing Supply	3.66 (.62)	3.58 (.64)
Improving Our Science	3.72 (.55)	3.49* (.68)
Being Vigilant	3.59 (.71)	3.46 (.68)
Protecting Our Homeland First	3.54 (.80)	3.42* (.83)
Protecting Individuals	3.75 (.57)	3.41* (.78)
Assuring Fairness	3.69 (.65)	3.33* (.80)
Tackling the Biggest Problems First	3.67 (.59)	3.27* (.82)
Saving Medical Costs (St. Louis)	3.51 (.749)	3.16* (.883)
Reduce Medical Costs (Columbus & Syracuse)	3.71 (.53)	3.57* (.76)
Obtaining Greater Protection Now (St. Louis)	3.56 (.729)	3.41 (.760)
Greater Protection Now (Columbus & Syracuse)	3.55 (.71)	3.29* (.85)
Helping Others (St. Louis)	3.72 (.553)	3.37* (.803)
Helping Other Countries (Columbus & Syracuse	3.27 (.77)	2.90* (.89)

* indicates significant change at p<.05

Participants were asked to rank order 12 areas based on priority at the beginning and at the end of each meeting. Rankings were from "1" (most important) to "12" (least important). "Make vaccine affordable and available to everyone" was rated the most important area both on the pre-test and the post-test, and "Assure compensation for those injured by vaccines" was rated least important. The evaluation ratings were consistent with the electronic polling; the top five areas were the same for both, although in slightly different order. There were two areas that changed significantly from the pre-test to the post-test across all three sites: "Improve vaccine safety" and "Assure compensation for those injured by vaccines." Both of these decreased in importance from pre-test to post-test (see Table 11).

Table 11
Rating of Priority Areas Before and After Deliberation Meetings

Priority Areas	**Pre-test Mean (Std Dev)**	**Post-test Mean (Std Dev)**
Make vaccine affordable and available to everyone	3.77 (3.47)	4.04 (3.84)
Assure there is enough vaccine	5.20 (3.36)	5.19 (3.26)
Maintain high rate of vaccination of children	4.78 (3.59)	5.27 (3.35)
Improve vaccine safety	4.34 (3.63)	5.54* (3.70)
Improve monitoring of disease and vaccines	6.09 (3.73)	6.08 (3.46)
Improve the information offered about vaccines	6.65 (3.89)	6.26 (3.68)
Develop new vaccines	5.97 (3.66)	6.27 (3.18)
Improve tools for making vaccines	6.64 (3.54)	6.34 (3.33)
Increase vaccination of adolescents	6.69 (3.40)	7.13 (3.37)
Increase vaccination of adults	7.54 (3.31	7.37 (3.32)
Help other countries reduce diseases through vaccination	7.82 (3.62)	8.37 (3.57)
Assure compensation for those injured by vaccines	7.93 (4.08)	8.87* (3.73)

* indicates significant change at p<.05

Changes by Different Groups

We examined whether the geographic and demographic backgrounds of the participants made a difference in perspectives about values and priority areas. In theory, if there are minimal differences across demographic groups of participants, public engagement conveners would not need to be too concerned about ensuring participants represent a diversity of perspectives or backgrounds. If, on the other hand, there are substantial differences in perspectives across demographic groups, it may become more important to ensure there is diverse representation of participants and that deliberations are conducted in different parts of the country.

We found significant differences across the three deliberation sites in the post-meeting rating of social values ($F(22,308) = 2.655$, $p < .001$)**.** For example, participants in St. Louis and Columbus rated "Protecting our homeland first" as more important than participants in Syracuse; participants in Syracuse rated "Improving our Science" as more important than citizens in St. Louis or Columbus; participants in Columbus rated "Securing supply" as more important than citizens in Syracuse. There were also significant differences in how citizens ranked priority areas across the three sites ($F(24,302) = 3.104$, $p < .001$). Citizens in Syracuse ranked "Improve vaccine safety," "Improve monitoring of disease and vaccines," and "Improve the information offered about vaccines" higher than did participants in Columbus or St. Louis; this is consistent with the observation that many Syracuse participants were concerned by the link between vaccines and autism. It appears, then, that conducting public engagement in different geographic locations may be important to obtain varied perspectives.

Ratings of values and rankings of priority areas also differed significantly across demographic groups. For example, post-meeting ratings of values differed by level of education ($F(33,459) = 1.676$, $p = .012$). Participants with some graduate school or a graduate degree rated "Protecting our homeland first" and "Securing our supply" as significantly less important than participants with lower levels of education. Ratings of values also varied by income level ($F(22, 336) = 1.753$, $p = .020$). Citizens earning less than $30,000 per year rated "Protecting our homeland first" higher than participants with higher incomes and rated "Improving our science" lower. Responses varied by race/ethnicity as well ($F(33, 531) = 1.652$, $p = .014$); for example, participants of "other" race (using categories of Hispanic, Non-Hispanic Whites, Non-Hispanic Blacks, and Other) rated "Protecting the most vulnerable" significantly higher than Non-Hispanic Whites. The rating of values did not vary significantly by gender or whether participants had children living at home. Although there were significant differences in ratings of social values across certain demographic groups based on geographic location, income, education, and race/ethnicity, there were no significant differences for the ranking of priority areas across demographic groups except, as discussed above, across the three meeting locations. These results provide evidence that diversity of backgrounds has some bearing on the perspectives brought to public engagement processes. This appears most important for geographic location, and somewhat less so for race/ethnicity, income level, and education.

Chapter 6: Evaluation Results – Quality of Deliberations

Summary of Findings

- Participants perceived the process to be of high quality.
- Satisfaction was consistent across demographic groups.
- The level of satisfaction varied by meeting location; although, it is unclear whether this can be attributed to differences in process across the meeting sites or different types of individuals attending the meetings
- The most common criticism of the process concerned difficulty understanding the values

Process Ratings

The post-surveys indicate participants generally believed the process was of high quality. Table 12 shows average scores for ratings of the process on a scale of one to four, with four representing agree strongly and one representing disagree strongly. For the first six items, a higher quality process is associated with a higher numerical score. For the last two items (in bold), a higher quality process is associated with a lower numerical score. In all three cities, citizens rated the process high on all dimensions. The highest rated dimensions were that participants felt comfortable talking, thought others felt comfortable talking, and thought the discussion was fair to all participants; the lowest rated dimension was that one person or a small group of people dominated the discussion.

There were differences across the three sites. Overall, citizens participating in the Columbus meeting were most satisfied with the process and citizens from Syracuse were least satisfied. It is unclear if these differences are the result of differences in the process used in each meeting or differences in the participants; as discussed previously,

there were fewer participants in Syracuse, they were less racially and ethnically diverse, more highly educated, reported higher incomes and were not offered compensation for their participation. In addition, it appeared many of the Syracuse participants had concerns about vaccine safety, particularly in relation to autism.

Table 12
Citizen Ratings of Process by Meeting Location

Statement	Overall (n=192)	St. Louis (n=77)	Columbus (n=74)	Syracuse (n=41)
I felt comfortable talking in this discussion.	3.77 (.50)	3.69^ (.61)	3.89* (.31)	3.71^* (.51)
I think other people in this discussion felt comfortable talking.	3.67 (.61)	3.58^ (.68)	3.74^ (.53)	3.68^ (.61)
This discussion was fair to all participants.	3.65 (.66)	3.64^* (.76)	3.78* (.50)	3.44^ (.67)
This process produced a valuable outcome.	3.41 (.75)	3.23^ (.94)	3.66* (.53)	3.29^ (.56)
This process helped me better understand the types of trade-offs involved.	3.36 (.79)	3.22^ (.88)	3.61* (.62)	3.17^ (.77)
This process has produced credible, relevant and independent information.	3.31 (.79)	3.17^ (.94)	3.62* (.52)	3.00^ (.71)
Important points or perspectives were left out of the day's discussion.	2.09 (1.07)	2.32^ (1.13)	1.82* (1.06)	2.15^* (.88)
One person or a small group of people dominated the discussion.	2.07 (1.12)	2.18^ (1.12)	2.00^ (1.17)	2.00^ (1.05)

*^ items without the same symbol are significantly different at p<.05

We examined the perceptions of quality across demographic groups. There were no significant differences by gender, age or race/ethnicity; males and females, persons of all age groups, and persons across racial/ethnic groups had equivalent levels of satisfaction with the process. There were, however, significant differences based on education ($F(36,525) = 1.468$, $p = .041$) and income ($F(24, 338) = 2.531$, $p < .001$). Participants with lower levels of education tended to agree more than highly educated participants with the following statements:

- This process has produced credible, relevant, and independent information
- This process helped me understand the types of tradeoffs involved

Participants with lower annual incomes were more likely than higher income participants to agree with the following statements:

- The discussion was fair to all participants
- This process produced a valuable outcome

- This process has produced credible, relevant, and independent information
- This process helped me understand the types of tradeoffs involved

Perceptions about the Process

Most comments about the process in general were positive. Participants described it as an "empowering, educational, participatory experience." They left the day with a sense of what it felt like to make difficult decisions: "I got a taste of lawmaking." "It helped us to see maybe what the President and Congress have to go through." "Maybe we should have more patience with leadership that makes these decisions."

There were a number of participant suggestions and comments about the process centered on the small group exercise in which note cards with values listed on them were used to stimulate discussion about priorities. The primary source of confusion experienced by participants stemmed from the examples used to illustrate the values: "The labels were frankly terrible." "A lot of people at my table had a hard time understanding the cards." "The titles on the cards were not clear. Perhaps better examples would have helped?" "The language level was too hard for the group. A lot of really big words were thrown about. And things were going so quickly there wasn't time for people to raise hands and ask questions." As one organizer stated, "What was the biggest problem and biggest flaw was the people's interpretations of what these things were, were completely different."

In addition to the perceived disconnect between the stated value and its example, many of the focus group participants believed fewer values would have been easier to discuss and prioritize in the time they were allotted for the activity. Key stakeholders and organizers of the event recognized the problem participants had with the cards after the first event, but decided to keep the exercise constant to allow comparison across sites. They did however make some changes to the values exercise which made it easier in the subsequent discussions. After all the discussions had been completed, one organizer suggested it may be better to "let the citizens generate their own values about what is important to them, perhaps with some prompts in the background with facilitation." Some participants found the value cards helpful when it culminated at the end of the day with an exercise matching it with the vaccine plan elements.
"I wouldn't have expected those decisions. Just looking at the list I would have picked some things, but when I had to match it with the things we picked from the morning it was different."

From the observations of the evaluation team, the ORISE team provided excellent logistical support overall, and effective logistical administration should be considered a fundamental requirement of a satisfactory public engagement process. Important components of logistical administration should include having an appropriately large forum, and proper audio/visual facilities and administration. In one location, several participants complained that the video screen was too small: “Our table was on the other side of the room and could hardly see the screen. They should have had a bigger screen.” Particularly as power point presentations and electronic voting play an important role in the engagement process, having a large enough screen—or multiple screens displayed in the forum—should be a priority. In another location, the heat was not turned on for several hours, and both participants and event staff had to don their winter jackets to stay warm. Prior to entering into relationships with local partners, certain logistical requirements that constitute a satisfactory event forum should therefore be identified. In one location, citizens complained about the noise level when small groups were deliberating.

There were varied relationships between the federal conveners and local partners. Local partners did a very good job with event administration overall, particularly with recruitment of participants and facilitators. There was high praise among participants for the quality of small group facilitating overall, which reflected the fact that many of the small group facilitators had had prior experience in facilitating discussions. In one forum, there was disagreement between the federal and local conveners about the offering of a financial stipend to participants, as well as to the focus of recruitment generally. The differences in recruitment strategies in this site may account for the fact there was significantly less turn out among participants. Because a recruitment strategy is crucial to the success of an effective engagement process, the components of that recruitment strategy should be identified well in advance and must be made clear to local event partners. Fundamental components of the recruitment strategy—for example, that a financial stipend will be offered to participants—should be considered a required component of an engagement process prior to entering into an agreement with a local convener.

Chapter 7: Evaluation Results – Perceptions about Use of the Public Input

Summary of Findings

- Participants thought public officials would use their input and that the process would increase public support of policies
- Evaluators suggest a feedback process to communicate how input was used by decision makers

Participants were asked to give their opinions about the degree to which they thought officials would use their input and whether the process would result in more public support for the policy decision. Citizens rated these items on a one to four scale with one indicating disagree strongly and four indicating agree strongly. Table 13 indicates that participants thought their input would be used and the process would increase public support.

Table 13
Participant Perceptions of How Information Will be Used

Statement	Overall (n=192)	St. Louis (n=77)	Columbus (n=74)	Syracuse (n=41)
Officials will use our input in their decisions.	3.18 (.86)	2.99^ (1.02)	3.47* (.69)	3.02^ (.69)
This process will increase the public's support of the decision ultimately made.	3.13 (.85)	3.06^* (.94)	3.34* (.75)	2.85^ (.79)

*^ items without the same symbol are significantly different at p<.05

There were significant differences across meeting locations. Citizens in Columbus were most likely to agree with both statements. There were no significant differences based on gender, age, race/ethnicity, child living at home status, or education. However, there were differences based on income. Persons of lower income agreed with both statements more than participants with higher incomes.

Participants in focus groups from all cities expressed hope that decision makers would use the information from the events.

"Some presenter said 'If we use your information' and that scared me that maybe I would not be heard. I hope it's used."

> "It's important that policymakers do follow public opinion because we are the ones that can choose to not follow recommendations they make. If they don't listen to us then we won't get ourselves or our kids vaccinated."

Key decision makers interviewed as part of the process expressed the same cautious optimism as participants about how public input will be used. They stressed the importance of involving the public, but indicated that it is only one of many voices that will be considered when revising the national plan. One decision maker likened it to a “four legged chair” as the voices of the public are combined with input from the Institute of Medicine, experts inside government and experts and stakeholders outside of government. Another federal policy maker cautioned about unrealistic expectations that any source of input would have any type of immediate and major impact:
"Some ships are very nimble and can shift on a dime, like a sailboat. But when you have an enterprise that is much more like an aircraft carrier it’s going to take a long time to shift, especially in vaccine development where you have a 10, 15, 20 year timeline as well as a really complicated system here in the U.S., the ship is more like an aircraft carrier than a sailboat."

Chapter 8: Summary of Lessons Learned

The general impression of decision makers and organizers about the process used to gather public input via the engagement activities was that it was successful; however this conclusion was delivered with caveats. The snapshot gained from the three cities was not viewed by decision makers as scientifically valid from a sampling perspective, though it was viewed as reasonable given the budget and time constraints of this project. There was also doubt from some decision makers because the conditions were slightly altered among the sites, e.g., compensation was not offered in one site. Evaluation results confirm differences across sites and across demographic groups.

There was general agreement that decisions at the policymaking level should be made prior to gathering public input about what the objectives of obtaining the sought-after public input are, and how that input will be used in decision-making. On both conceptual and practical levels, there is no consensus about the types of policy areas that are appropriate for deliberative discussions as a form of public engagement to inform policymaking. One federal decision maker indicated that obtaining public input through deliberative processes is valuable when critical issues about policy are yet undecided, rather than using it to address issues in which a decision has already been determined through expert involvement. Another decision maker said that even with expert determinations it is critical to involve the public and gain their perspective. This person said that in the past, recommendations from experts were considered the "gold standard" and that there has been an assumption that lay persons do not possess the deep knowledge needed to make good recommendations or to help prioritize issues. However, the decision maker contends that the role of the public is not to contribute expertise, but instead to understand the cost/benefits of decisions and render an opinion. The example used to illustrate this point was the decision to choose which is more important, to go to a baseball game or out to dinner. In the past, experts got to decide what is important to them, but the public did not. A room full of

restaurant and baseball team owners would benefit from understanding how the public prioritizes the decision, just as scientists and government officials will benefit from hearing the public perspective related to the national vaccine plan.

General themes arising from interviews with decision makers and organizers included:

- Pre-identifying the purpose and use of public input will make it easier for decision makers to use the information and will clarify for the public what their input will influence.
- A deliberative process may not be necessary for all public input desired by government agencies. The process should be matched to the type of desired input.
- Creating a common understanding of terms and definitions to describe values is critical.
- Structuring engagement processes through the use of consistent recruitment strategies and activities will increase the generalizability of the information gained from the process.
- Increasing use of deliberative processes to influence policy will require champions within government to advance its use and to educate decision makers about its value.
- Attention to detail is important to achieve good outcomes (e.g., skilled facilitation; orientation for resource personnel; appropriate room set up and acoustics; recruitment to achieve adequate representation of all groups).
- Involving local convening partners at an early stage is important, as is having clear agreements with them about recruitment of participants and event logistics well in advance of deliberation dates.
- Recruitment of participants should include strategies for obtaining diversity in race/ethnicity, socioeconomic and educational status, and gender. Starting the recruitment process early and using stratified random sampling can assure a distribution of participants based on desired characteristics. This type of recruitment process, however, results in a longer time to reach participation goals and turning away certain individuals who are interested in participating.
- Replicating deliberative processes with expert stakeholders will allow decision makers to compare and contrast it with public input.

Themes about the process included:

- Rapid input through the use of the real time voting was beneficial because participants and conveners knew what preferences were.

- Observers and subject matter experts present at all the meetings were beneficial to the discussions and participants.
- Values definition cards could/should have been more thoroughly pretested and vetted before used.
- The team of organizers worked very well together and the division of labor between process designers and logistics was beneficial.
- The exercises were creative and challenging, and raised the bar on public engagement activities.
- It is important to identify the core, non-negotiable items that are essential to convening successful deliberative events in agreements with local conveners well in advance – This is especially the case with recruitment, which is a critical component of a successful deliberation. A uniform recruitment strategy across sites is key to the validity of the project.

Themes arising from the participant focus groups and evaluation instruments included:

- Knowledge about the policy topic increases as a result of public engagement processes.
- Diversity of opinion and perspective is important to participants and to organizers.
- Compensation of participants increases demographic diversity.
- Values shift as a result of participating in a deliberative process.
- Information to educate participants should be presented using adult education principles to ensure all learning styles are accommodated.
- Having evaluators participate in planning meetings contributes to a clearer understanding of project goals, rationale for process design, more relevance to evaluation questions and method, and smoother integration of the evaluation into the public engagement process.

Chapter 9: Conclusions

The deliberative process to obtain public input for national vaccine policy met its major goals, although to varying degrees. Organizers were generally successful at attracting citizens to participate in deliberative days in three locations – St. Louis, Missouri; Columbus, Ohio; and Syracuse, New York. The goal was to attract about 100 citizens to participate in each meeting. This goal was met or nearly met in two of the locations (St. Louis and Columbus), but not the third – Syracuse. There were, however, enough citizens even in the Syracuse meeting to have large group discussions and to break out into small groups for dialogue. Partners in each city led recruitment efforts; there were differences across the three sites in recruitment techniques which likely contributed to the smaller numbers in Syracuse, One important difference was that participants in Syracuse were not offered a stipend for their participation. Standardizing recruitment procedures and providing a standard stipend likely would have resulted in greater participation in Syracuse. There was also about a 15% attrition rate – participants who left before the completion of the process. Requiring participants to attend the entire meeting before they receive their incentive is a strategy likely to decrease the attrition rate. Participants were motivated to participate by an interest in the topic, believing they would learn more about the topic, the stipend in two of the cities, and through a feeling of civic duty or public responsibility to participate in the process.

The process was also generally successful at recruiting a diversity of citizens to the three meetings. Participants represented a diverse mix of demographic backgrounds, although they did not mirror the characteristics of the communities within which the meetings were held. Males were underrepresented in all three meetings. Racial and ethnic minorities were overrepresented particularly in Columbus and St. Louis. Participants also tended to have higher levels of education than the general population, particularly in Syracuse. Although there were demographic differences across the three sites and between participants and the meeting communities, participants came from across the age span, from a variety of racial/ethnic groups, and across the income and education spectrum. Participants were in general agreement that the citizens participating in the meetings represented a diversity of perspectives and expressed a variety of views. Some of the participants noted that although citizens attending the meeting tended to be diverse, the meeting organizers and presenters appeared less diverse. The two communities with more racial, ethnic, educational, and socioeconomic diversity tended to have more varied efforts for recruitment. A stratified random sampling process could be used in future public engagement efforts to help ensure appropriate diversity of participants.

The process was successful at increasing the knowledge level of participants. Knowledge increased significantly at all three meeting sites as a result of information provided to participants and the discussions that ensued. The process was not, however, successful in elevating all participant knowledge to the same level. In fact, there was a greater

disparity in knowledge at the end of the meeting than at the beginning. All demographic groups tended to increase their knowledge at about the same rate. In other words, those groups that had the least knowledge going into the meeting (e.g., persons with less than high school education) increased their knowledge during the meeting, but still had the lowest level of knowledge at the end of the meeting. If it is desirable for all participants to have an equivalent level of knowledge about the topic, future public engagement processes might consider providing information that is able to be easily comprehended by all groups. Some participants thought the presentations were too complex and the language level was too high. However, participants thought they had adequate knowledge to engage in informed discussions. Interestingly, groups who did less well on the knowledge questions were those who were most confident in their knowledge about the subject matter. The evaluation findings suggest information presented should be tailored to participants with lower education levels.

As a result of the process, participants exhibited a change in opinions about social values as well as some priority areas related to vaccine policy. For example, the social values of "protecting our homeland first," "assuring fairness," "emphasizing safety," "tackling the biggest problem first," "protecting individuals," "and "improving our science" were rated as less important after citizens engaged in the deliberative process. Participants perceived that their opinions changed as a result of listening to the opinions of other participants and having to make choices among different options. These results support the conclusion that obtaining input from citizens and stakeholders who are informed and engage in dialogue yields different results than simply surveying and polling the public. The evaluation also revealed, perhaps not surprisingly, that citizens from different geographic area, racial/ethnic backgrounds, income and education levels had different perspectives about social values and priorities. This finding reinforces the need to include citizens from diverse backgrounds in public engagement processes to obtain varied perspectives. The evaluation results also support conducting deliberative processes in multiple jurisdictions. Interestingly, the evaluation did not appear to result in a "meeting of the minds" among participants with respect to the values used to make policy decisions or in the areas identified as priorities; in fact, there was a wider range in opinions about underlying values at the end of the deliberations than at the beginning. This result may have been due to confusion surrounding the values exercise. However, even for the priority areas, we did not find a consistent converging of perspectives.

The deliberation process was perceived to be of high quality. We believe this was true in large part to the level of planning of project organizers and facilitators prior to the meetings. Participants rated the process high on a number of dimensions. For example, citizens and stakeholders thought participants felt comfortable talking in the meeting, the discussion was fair to all participants, and the process helped them understand the types of trade-offs involved in developing priorities for national vaccine policy. There were differences across the three sites with citizens from Syracuse being the least satisfied. In addition, there were differences in satisfaction based on level of education, with more highly educated persons tending to be less satisfied. We found no significant differences in satisfaction for other variables such as race, gender, income, age, and whether they had children at home; this finding indicates that the process was considered high quality across groups. Overall participants thought the process was empowering and educational. Suggested improvements to the process centered primarily on improving the process for developing and prioritizing values.

Citizens thought their input would be used by decision makers and thought it would be important for policy to reflect the opinions of ordinary citizens. The process appeared to create an expectation by participants that the input would be given serious consideration in developing national vaccine policy. It is unclear what feedback process is planned for informing participants how the results of their deliberations were actually used when the vaccine plan is issued, but this step would appear to be important to reinforce the value of each citizen's participation, to build trust with government, and to build support for public engagement efforts. In this evaluation, we were not able to determine how the results of the citizen deliberations were actually used by decision makers.

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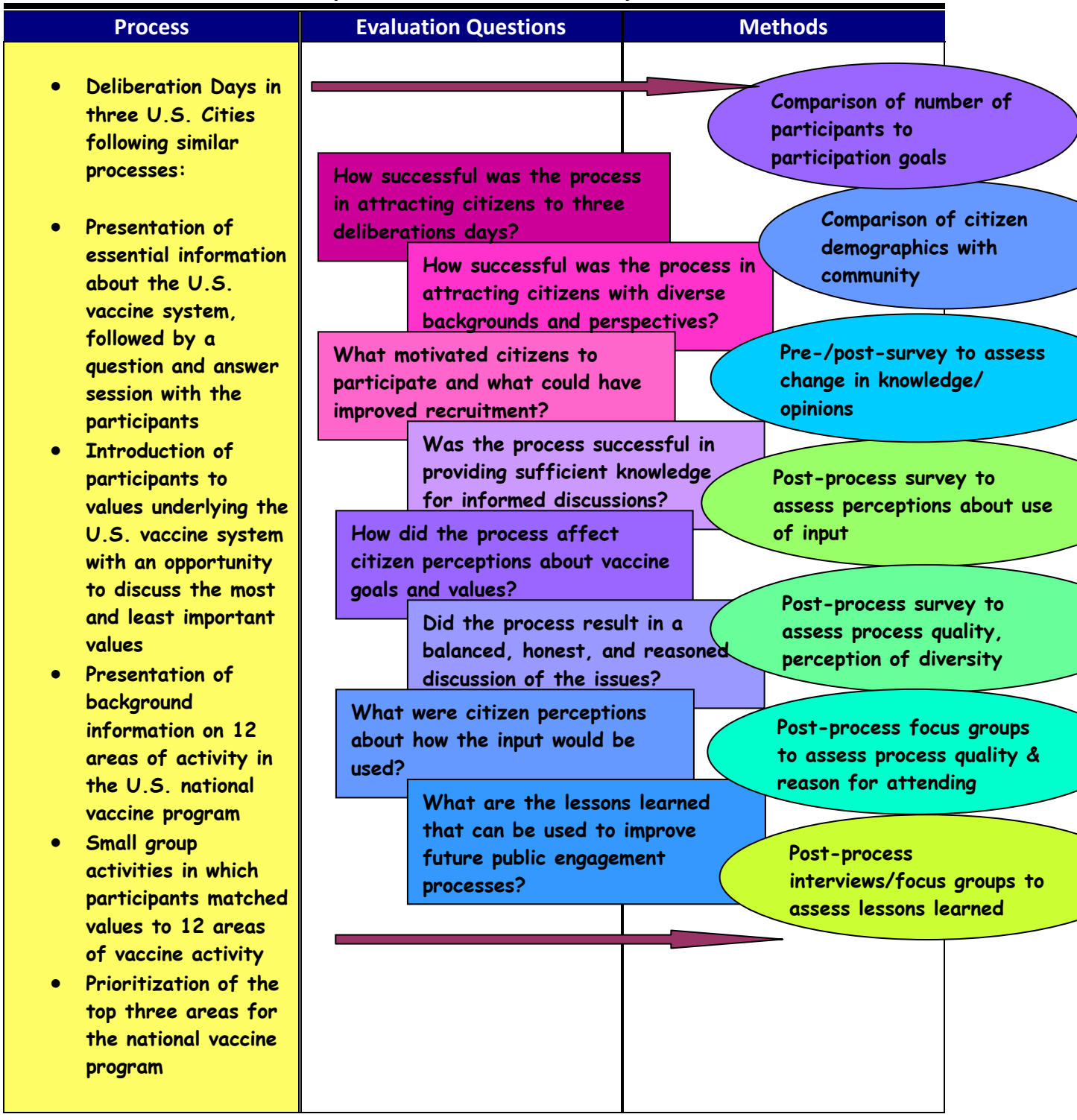
Appendix 1: Logic Model for the Evaluation of the Deliberative Process to Obtain Citizen Input on National Vaccine Policy



Appendix B. Agenda and Facilitation Script

Facilitation Script

National Vaccine Plan (NVP)
Deliberation Day—March 28, 2009
Columbus, Ohio
8:30 a.m.–4:30 p.m.

Assumptions:

1. 100–120 people—divided into 10–14 groups of 9 participants/group. Facilitators are at each table. Participants are preassigned to tables.
2. Participant kits provide information about the NVP, the day itself, and the dialogue ground rules.
3. Participant voting is done through the use of handheld devices (called "clickers") and results are displayed on the screen.

Process Outline:

8:30–9:00
Pre-session assessment
Prior to any discussion, participants will provide their initial or "top of mind" ranking of the areas of activity in the NVP.

9:00–9:25
Welcome and introductory remarks
To be provided by an HHS/NVPO representative and the lead facilitator for the event.

9:25–10:10
Essential information about the U.S. vaccine system today
A presentation in layperson terms about the national immunization system, including macro-level trends and realities that are impinging on the vaccine program today. This information is to allow participants to obtain a general sense of the status of the current immunization system in the U.S. prior to having a discussion about what participants value most about such a system.

10:10–10:35
Identifying what matters
In this session, participants will surface and identify the aspects of the U.S. immunization program that they value and develop a shared understanding among themselves of what is meant by each of the important values identified.

10:35–10:50
Break

10:50–11:45
Identifying what matters (continued)

11:45–12:15
Consider and vote on the four most important public values around vaccines
In this session, participants will consider the positive and negative aspects of focusing on different values and decide which smaller subset of values matters most to them in a national immunization program.

12:15–1:00
Lunch

1:00–1:30
Consider and vote on the four most important public values around vaccines (continued)

1:30–1:50
Essential information about the 12 proposed areas of activity
A presentation in layperson terms about the proposed areas of activity in the national plan.

1:50–2:45
Discussion of the 12 proposed areas of activity in the NVP
In this session, participants will review the areas of activity proposed for the national plan and discuss how well or poorly each of the areas of activity fits with the previously chosen subset of guiding or paramount values.

2:45–3:00
Break

3:00–3:30
Determine the best fits
In this session, participants discuss and then vote on the four best fits between the values and the 12 proposed areas of activity in the NVP.

3:30–4:00 (if time permits)
Vote on the highest priority areas of activity in the NVP
In this session, participants will decide which areas of activity in the national plan they would give priority to, given a scenario of new funding.

4:00–4:15
Final debriefing
In this session, participants will provide comments on the process and outcomes of the day.

4:15–4:30
Final assessment
In this session, participants will repeat their earlier pre-event assessment but from the perspective of persons who have had the benefit of the day's deliberations

TIME	*CONTENT & PROCESS*	*NOTES*
Pre-session assessment In this session and prior to any discussion, participants will provide their initial or "top of mind" ranking of the areas of activity in the NVP.		
8:30–9:00	**Continental Breakfast** • Registration—people assigned to a small table group • As individuals arrive, they are asked to complete a pre-questionnaire and a consent form. The questionnaire includes o 8–10 multiple-choice knowledge questions o Ranking of the 12 areas of activity o Demographic data o Values questions • People receive their clickers (for the keypad voting) at registration. Their clicker number is the personal identifier that they use for all questionnaires so a comparison can be done to see if individual views have changed.	First rating gives the "top-of-mind baseline" before any information has been provided or dialogue occurred. Facilitators circulate, picking up completed questionnaires.
Welcome and introductory remarks To be provided by an HHS/NVPO representative and the lead facilitator for the event		
9:00 –9:25	**Welcome and Introductions** ➢ Welcome and context for the deliberation o Ray Strikas, NVP, who introduces the team, observers, and resource people o Columbus host(s) who introduces the team of local facilitators ➢ Overview of agenda and discussion guide; request return of all pre-questionnaires and the consent form; note this is the second of three dialogues and that a report detailing the findings and advice from citizens will be prepared and sent to all participants. The role of plenary note taker and the principle of anonymity are flagged. o Jacquie (plenary facilitator) ➢ In small groups, table facilitators do a round of introductions with each person commenting on o Name o Why he/she came (e.g., one interest attendee has about the topic) ➢ Introduce the clickers and do a check-in of who is in the room (1 minute/question). o How many coffees did you have today? (0, 1, 2, 3, 4, or more!) o Identify which table you are sitting at. o Gender? F/M o Press letter for age range.	There is a facilitator at each table. Please make sure that all the people at your table have completed the pre-questionnaire and the consent form. Ask them to record their clicker number on their participant kit. Introduction – 30 seconds per person at round tables Facilitators, for the opening round of introductions, please record people's comments using Worksheet #1.
Essential information about the U.S. vaccine system today A presentation in layperson terms about the national immunization system, including macro-level trends and realities that are impinging on the vaccine program today		

TIME	*CONTENT & PROCESS*	*NOTES*
9:25–10:10	**Information Session** ➢ Presentation—Bill Atkinson, National Center for Immunization and Respiratory Disease—20 minutes ➢ Plenary Q and A—Jacquie collects 2–3 questions for Bill to respond to in plenary session. ➢ At 9:55–10:00, if there are still several questions, resource people circulate to tables where there are other questions. Jacquie notes that resource people are also available during small group work if there are additional questions. (For questions remaining at 10:10, Jacquie suggests people write them up on blank cards at the table. Facilitators collect them for review by resource person. Any critical ones are responded to in plenary session after lunch.)	"Mike runners" move the mike from questioner to questioner.
Identifying what matters In this session, participants will surface and identify the aspects of the US immunization program which they value and develop a shared understanding among themselves of what is meant by each of the important values identified		
10:10 –10:15	**Overview of the Process (**Jacquie) ➢ Introduction to dialogue and the ground rules. ➢ Introduce the concept of values and note that there are several values that underlie the NVP. The first activity helps you explore those values, developing a shared understanding of what they mean for your group in the context of this issue. You'll also be able to explore how you might weight the relative importance of these values as they apply to the NVP. ➢ Introduce the working assumptions for the day. 1. *States will continue to require certain vaccines for school and day care attendance.* 2. *The federal government will continue to provide financial support to state immunization programs.* 3. *The federal government will continue to provide support for children who cannot afford vaccines.*	PowerPoint of dialogue vs. debate chart; ground rules; working assumptions

TIME	*CONTENT & PROCESS*	*NOTES*
10:15–10:35 *(Participants work at round tables.)*	**Identifying What Matters Most** **10:15 – 10:20** ➢ Jacquie asks facilitators to distribute the packs of cards at their round tables. She then reviews the cards one by one using Power Point slides. *On each card you'll find a value that might be considered important as we consider the national vaccine plan and a descriptor of that value. There are additional cards for people to write down additional values (one value per card) if they think an important one is missing.* ➢ She goes through the instructions for the small group activity, which are also on a PowerPoint. She notes that the facilitator at each small table will help the group work through the activity. ➢ She asks each table to recruit a volunteer note taker from the table and notes that the role of note taker can be shared among the table members through the course of the day. The note taker's role is to capture the key points of discussion, using the work sheets provided. ➢ She asks people to remember the working assumptions and notes that, for the purpose of this activity, they can assume that they are thinking about the ideal program without consideration of cost. At round tables, table facilitators work their groups through the following: **10:20–10:35** As individuals, please read the statements on the cards carefully and split them up into three groups: • four cards that express the values that you think are the most important when considering the NVP • four cards that you think are least important • the others in a middle pile If you would like to add a new value, please use a blank card. (Participants can work into break if needed, but bring groups back to tables by 10:50.)	**Stages: Clarify perspective and comprehend what matters** PowerPoint of the cards and the activity instructions Each table has preprepared flip charts for the dot vote(s), and colored dots cut into fours. Resource people are available to answer questions at the round tables.
10:35–10:50	**Break** Over break, table facilitators let Jacquie know if there are any new values that could potentially be voted on in plenary session.	

TIME	*CONTENT & PROCESS*	*NOTES*
10:50–11:45	**What Matters Most** (continued) ➢ Facilitator (F) gives each person four dots and asks him/her to put them on the four values on the flip chart that he/she has out in his/her most important pile—only one dot per value. ➢ F asks people to examine the resulting vote, tallying the total number of dots per value. F asks the volunteer note taker to use work sheet 2 to record the key ideas coming from the discussion on the vote. ➢ Beginning with the value that received the most dots, F asks those who choose that value to explain why they have selected that value and how it relates to the NVP. Go through the top four values this way, clarifying what each value means to develop a shared understanding. ➢ F then asks if any participants would like to make a case for any of the other values. • Based on a dot vote, these are our group's top four values. Would anyone like to suggest that a different value should be in the top four? If so, why? • Which value would you suggest it replace? • What do others think of this idea? Pros? Cons? Trade-offs? ➢ F continues moving from one value to another according to how many values are proposed. Once the discussion is exhausted (or time runs out), ask for a second dot vote if necessary. (It's possible that the group may already have arrived at common ground through the discussion.) ➢ F asks for a volunteer to use the designated table clicker to express the group's top four values in plenary session. ➢ F asks if there were any new cards generated that have not already been discussed. These are noted. ➢ F asks people to keep their cards in their piles since they'll indicate their least important through a plenary vote.	Note takers use work sheet 2 Each table has a designated clicker that is used to record table votes (in contrast to individual votes).
Consider and vote on the four most important public values around vaccines In this session, participants will consider the positive and negative aspects of focusing on different values and decide which smaller subset of values matter most to them in a national immunization program.		

TIME	*CONTENT & PROCESS*	*NOTES*
11:4 –12:15 *List of values is in participant kit.*	**Selecting the Leading Values** ➢ In plenary session, Jacquie asks one person at each table to use a clicker to vote for that table's four values. ➢ In plenary session, examine the results of the vote, asking tables to indicate with raised hands which table voted for which (of the top four). Explore areas of divergences and determine areas of common ground, clarifying the values further if need be and the pros and cons of selecting certain values over others. *For example, how might the plan change if certain values were chosen over others? Who might win? Who might lose? Would you be willing to live with that?* ➢ If time permits, people could share reflections at their round tables. ➢ Using their individual clickers, each person is asked to vote for the four values he/she thinks are the most important ones to underlie the NVP. ➢ Using their individual clickers, each person is asked to vote for the four values that were his/her least important. Before lunch, Jacquie lets people know that the evaluation team is asking for a small group of volunteers to stay for another 30 minutes at the end of the day to be part of a focus group on the day. *If you are interested, please see one of the evaluators.*	**Stage: Commit to what matters most** Clickers 1–10 are the table clickers. Note taker continues to use work sheet 2 to collect key ideas at round table.
12:15–1:00	**Lunch**	
1:00–1:30	**Validation of Common Ground** In plenary session: • Show results of the least important vote. • Show results of most important. • Explore areas of similarity in the most important vote, and determine if there is a top list of four leading values. Work to have the group of 100 have a set that "they can live with."	
Essential information about the 12 proposed areas of activity A presentation in layperson terms about the proposed areas of activity in the national plan		
1:30–1:50 *List of activity areas is in participant kit.*	**Presentation on the Areas of Activity** Presentation, followed by Q&A • Ray Strikas, National Vaccine Program Office, HHS • As time permits, Ray also responds to any outstanding and critical questions written down from the morning.	
Discussion of the 12 proposed areas of activity in the national plan In this session, participants will review the areas of activity proposed for the NVP and discuss how well or not each of the areas of activity fit with the previously chosen subset of guiding or paramount values.		

TIME	*CONTENT & PROCESS*	*NOTES*
1:50–2:45 *Activity table is also in the participant kit.*	**Assessing the "Goodness of Fit" Between Values and Activity Areas** ➢ Jacquie explains the next activity. Steps and sample table are on a PowerPoint. She illustrates the rating process as described below by using a hypothetical example. She asks people to remember the working assumptions and notes that for the purpose of this activity, they can assume that they are thinking about the ideal program, without consideration of cost. **1:55–2:45** ➢ In their table groups, the facilitators help their groups consider the 12 activity areas in light of the four leading values agreed to in plenary session. They discuss how the areas relate to the values they consider to be of key importance and map out on preprepared flip charts which values relate most strongly to which activity areas. (The flip chart is a table with the values across the top and the activity areas down the side. Each small group determines the degree to which a value fits with the activity areas.) ➢ F asks for a volunteer note taker who uses work sheet 3 to record the key ideas discussed as the table is completed. **Process** ➢ Working *value by value*, table groups allocate a point value to each of the activity areas o 5 for a strong fit o 3 for a medium fit o 1 for a weak fit ➢ After each cell is completed, the table group adds up the points per activity area to see which ones have the best fit overall. ➢ F asks for a volunteer to use the designated table clicker to express the group's top four "best fits" in plenary session	***Stage: Choose to Act*** Process steps and sample table are on a PowerPoint. (See sample table below.) Each round table has a preprepared flip chart and a calculator. Note taker to use work sheet 3 to collect key ideas at round table. Can also get the group to quickly identify some of the easy 5s (e.g., the value of safety and activity area of improving vaccine safety).
2:45–3:00	**Break**	

Determine the best fits
In this session, participants discuss and then vote on the four best fits between the values and the 12 proposed areas of activity in the NVP

TIME	*CONTENT & PROCESS*	*NOTES*
3:00–3:30 *(longer if needed)*	**Determining the Best Fits** ➢ In plenary session, Jacquie asks one person at each table to use a clicker to vote for that table's four best fits (highest scoring based on row totals). ➢ In plenary session, examine the results of the vote, asking tables to indicate with raised hands which table voted for which (of the top four). Explore areas of divergences and determine areas of common ground**.** ➢ Invite tables whose areas of activity were not in the top four based on the composite rating to make their case for their lower-rated areas of activity if they desire. ➢ If time permits, people could share reflections at their round tables. ➢ Using the clickers, each person is asked to vote for the four areas of activity they think are the best fits overall.	Note taker may continue to use work sheet 3 to record table discussion
Vote on the highest priority areas of activity in the NVP—Scenario New Funding In this session, participants will decide which areas of activity in the national plan they would give priority to given the working assumptions and a scenario that current levels of overall federal funding will increase over what they are now.		
3:30 –4:00 *(If time permits)*	**Priority rating, based on a new money scenario** Scenario: Participants are told they can assume that the level of resources for the NVP will be increasing over what they are now. They are asked to consider the question: "If there were increased funding, which three areas would you like to see given priority for additional funding?" ➢ People are given a few minutes to consider it as individuals and then, using the clicker, people vote for their three key areas. ➢ In plenary session, present the results of the vote and compare to the strength of alignment arrived at earlier. ➢ Table group facilitators ask their small group to examine the results of the vote, using the following prompts: *Do the results reflect the values determined earlier? Why or why not? Do the resulting priority areas of activity provide the type of NVP you'd want to see for the country? What are the pros and cons? Would you be willing to live with that?* ➢ The vote is repeated.	Question is on a PowerPoint (Jacquie). Table facilitators ask for another volunteer note taker who uses work sheet 4 to record table discussion.
Final Debriefing In this session, participants will provide comments on the process and outcomes of the day.		
4:00 –4:15	At the small tables, table facilitators do a round of closing comments at the small tables. o Most important insight for you o Most important message that I would like to give decision makers	Table facilitators use work sheet 5 to record the closing comments.
Final assessment In this session, participants will repeat their earlier pre-event assessment but from the perspective of persons who have had the benefit of the day's deliberations.		

TIME	*CONTENT & PROCESS*	*NOTES*
4:15–4:30	Jacquie asks each person to complete a post-questionnaire. This mirrors the pre-questionnaire, including the ranking of the 12 areas of activity. There is room for them to comment as well. The questionnaire also includes evaluation questions. Jacquie reminds people that the evaluation team is asking for a small group of volunteers to stay for another 30 minutes to be part of a focus group on the day. Jacquie thanks everyone for their participation and lets them know that a report of all three dialogues will be sent to them all. Ray and the Columbus hosts add their thanks and close the session.	Table facilitators distribute the evaluation questionnaire and collect them when completed.

Public Values to Consider in Prioritizing National Vaccine Plan Activities

What Matters To Us	
1. Achieving Equity	• Make vaccines easily available and affordable for everyone in the U.S.
2. Protecting Our Homeland First	• Make sure people entering the U.S. are vaccinated, and American travelers are vaccinated before they leave the U.S.
3. Helping Other Countries	• Help poor countries to vaccinate their people. Help make vaccines for diseases common in other countries, but not in the U.S. (such as malaria).
4. Being Vigilant	• Measure how well existing vaccines are working in the U.S. and abroad. Work with others to identify new diseases in the world.
5. Assuring Fairness	• Compensate people injured by vaccines they were required to receive.
6. Emphasizing Safety	• Make vaccines even safer, even if it means that new ones take longer to develop or have to pass tougher tests.
7. Tackling Biggest Problems First	• Invest resources in new vaccines for common diseases, not rare ones.
8. Greater Protection Now	• Work to increase vaccination of teenagers and adults. Make better use of existing vaccines to protect more people.
9. Improving Our Science	• Increase research to better understand how vaccines work, and how they can be improved.
10. Promoting Education and Awareness	• Increase awareness of the benefits and risks of vaccines.
11. Securing Supply	• Improve our manufacturing and distribution systems to prevent shortages.
12. Protecting the Most Vulnerable	• Vaccinate persons who have increased risk for bad outcomes from disease, like the young, the old, and those with weak immune systems.
13. Protecting Individuals	• Conduct more research on why some persons have serious side effects and others do not.
14. Reduce Medical Costs	• Develop new vaccines that will help reduce the costs of treating illnesses.

Table Activity

For each box, please assign a number that indicates how good the fit is between the value and the area of activity for your group. Use the following scale:

- 5 for a strong fit
- 3 for a medium fit
- 1 for a weak fit

The total provides the overall goodness of fit between the values and the areas of activity.
Each proposed area of activity must obtain a total score between 0–20 points.

Proceed by selecting one value at a time and examining each of the 12 proposed areas of activity against that value.

Repeat the process of examining all 12 proposed areas of activity for each value identified.

Area of Activity	*Value* _____	*Value* _____	*Value* _____	*Value* _____	*TOTAL Score*
1. Improve tools for making vaccines.					
2. Increase vaccination of adults.					
3. Increase vaccination of adolescents.					
4. Make vaccine affordable and available to everyone.					
5. Maintain high rate of vaccination of children.					
6. Develop new vaccines.					
7. Assure there is enough vaccine.					
8. Improve vaccine safety.					
9. Assure compensation for those injured by vaccines.					
10. Help other countries reduce diseases through vaccination.					
11. Improve monitoring of disease and vaccines.					
12. Improve the information offered about vaccines.					

Example Table – Choosing a Vacation Destination

5 for a strong fit

3 for a medium fit

1 for a weak fit

Destinations	*Value* Entertainment	*Value* History	*Value* Nature	**TOTAL**
Las Vegas	5	1	1	7
Boston	5	5	1	11
Glacier National Park	1	1	5	7
Grand Canyon	3	1	5	9

Appendix C. Screening Instrument

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Screening Instrument

Deliberation Days: Public Values in National Vaccine Planning

Good evening. My name is _____ and I am calling from _____, a market research firm. We are talking today with people in the area as part of an event being conducted by the U.S. Department of Health and Human Services. We are not selling anything. We have a few brief questions and if you qualify and are interested, we will invite you to take part in a discussion group with other people in your area that will take place at a later date.

1. First, do you or does anyone in your household work for any of the following? **(THANK AND TERMINATE IF YES TO ANY OF THE FOLLOWING)**

   01 Advertising, public relations, and/or market research
   02 Any form of media—TV, radio, newspaper, magazine
   03 A health clinic, doctor's office, or hospital
   04 Other health-related field

2. How old are you?
   (RECRUIT A MIX REFLECTIVE OF THE COMMUNITY)
   (DOCUMENT ON GRID)
   01 Under 18 **(THANK AND TERMINATE)**
   02 18–34
   03 35–44
   04 45–54
   05 55–64
   03 65 or older
   96 Refused **(THANK AND TERMINATE)**

5. Document: Conversant in English?

   01 Yes **(CONTINUE)**
   02 No **(THANK AND TERMINATE)**

6. Document gender **(RECRUIT A MIX REFLECTIVE OF THE COMMUNITY)**
   (DOCUMENT ON GRID)
   01 male
   02 female

7. What was the highest grade or degree you achieved in school?
(RECRUIT A MIX REFLECTIVE OF THE COMMUNITY)
(DOCUMENT ON GRID)

01 High School diploma or less
02 One or more college degrees

8. What is your race?
(RECRUIT A MIX REFLECTIVE OF THE COMMUNITY)
(DOCUMENT ON GRID)
01 Caucasian
02 African-American
03 Hispanic
04 Asian
05 Mixed
06 Other _____

9. Do you have any special needs that need to be addressed for your participation, such as

01 hearing impairment Yes ___ No ___
02 wheelchair accessibility Yes ___ No ___
03 dietary restrictions _____
04 other _____

That is all of my questions. You do qualify for our discussion group, and we would like to invite you to join us on _____ at _____. The discussion will begin at 8:30 a.m. and end by 4:30 p.m. You must be 18 to attend this event. In appreciation for you time, you will be paid $XX at the time of the event.
Are you willing to participate?

01 yes
02 no

Appendix D. Participant Handouts

Table of Contents

DEPARTMENT OF HEALTH AND HUMAN SERVICES Office of the Secretary

Assistant Secretary for Health
Office of Public Health and Science
Washington D.C. 20201

Dear Participant:

Given the importance of vaccines and immunizations in the prevention of an expanding number of infectious diseases it is important that we, as a Department and as a Nation, clearly articulate our vision for the vaccine and immunization enterprise. In my role as the Acting Assistant Secretary for Health and the Director of the National Vaccine Program, I have directed and monitored efforts to update the 1994 National Vaccine Plan.

The current draft strategic National Vaccine Plan reflects priorities and potential future directions for the next decade. This draft plan offers a clear signal about our goals for vaccines and immunizations to our domestic and international partners in the United States vaccine and immunization enterprise. It is a strong beginning, but requires extensive consultation with and input from many partners, including members of the public. I want to thank you for taking time from your busy schedule to join staff of the Department of Health and Human Services in discussions regarding this draft plan.

The work you do today will help assure that the final plan benefits the citizens of this Nation by providing a comprehensive plan for addressing the prevention of infectious diseases.

Sincerely yours,

Steven K. Galson, M.D., M.P.H.
RADM, USPHS
Acting Assistant Secretary for Health

Purpose of the Dialogue

You have been invited as part of a group of adults, demographically representative of your city, to explore the values and priorities that you believe should guide your government as it renews and revises our country's National Vaccine Plan. Organized by the National Vaccine Program Office of the U.S. Department of Health and Human Services (HHS), this session is one of three citizen dialogues being held in the country.

The results of your deliberations will be considered, along with the input received from stakeholders and experts, by the National Vaccine Advisory Committee in the development of the new National Vaccine Plan.

The day ahead of you will be intense, sometimes energizing, sometimes frustrating, but we hope very rewarding and fruitful. In the morning, you'll have a chance to learn about the current vaccine program and ask questions. Then, at round tables, you'll consider what matters most to you, that is the values, that you think should guide the development of the new vaccine plan. You'll have a chance to work through these ideas with other participants and talk together.

By the end of the morning, you'll have explored your own views, your table's views and the full group's ideas about what is most important. We'll use keypad technology to vote on these values and arrive at 5-6 leading values.

In the afternoon, you'll hear about the twelve areas of activity that underlie the national vaccine plan and be able to ask questions. Then you'll have a chance to apply your leading values to these twelve areas of activity. Based on this alignment, you'll determine what priority you'd give to the areas of activity under two different scenarios. You'll share these with the other groups and get their input.

By the end of the day, you'll be able to offer some clear advice about which values and priorities you would like to see reflected in the government's decision-making. Whatever the outcome, you'll help give government a better understanding of the trade-offs and choices people are prepared to make and which they expect to be considered by government in renewing the plan.

Agenda for the Day

8:30 – Registration; Initial Questionnaire

9:00 am – 10:35 am

Welcome and Opening

Participant Introductions

Learning About the US Immunization System

- Presentation: An Overview of the State of Vaccines and the US Immunization System

Overview of the Process
Identifying What Matters Most To Us About Our Immunization System

10:35 – 10:50
Break

10:50 am – 12:15

Identifying What Matters Most To Us About Our Immunization System (continued)

Selecting Our Leading Values

12:15– 1:00 pm

Lunch

1:00 – 2:45

Validation of "Common Ground" (shared values that could guide decision-making)

Presentation: Overview of the Proposed Areas of Activity in the Draft National Vaccine Plan
Determining Which Areas of Activity Best Fit With What Is Most Important to Us

2:45 – 3:00

Break

3:00 – 4:00

Determining Which Areas of Activity Best Fit With What Is Most Important to Us (continued)

Determining Which Areas of Activity Would Be Most Worth Spending New Money On

4:00 – 4:30

Closing Comments – Participants

Closing Comments – Facilitators and Hosts

Closing Questionnaire

What is Dialogue?

The discussion that you and your fellow citizens will be having is designed to be a dialogue. Dialogue is a special kind of conversation that involves learning together and working to understand different points of view to try to build common ground. Dialogue is very different from debate, as shown in the chart below.

Debate vs. Dialogue	
Debate	Dialogue
• Assumes there is one right answer (and you have it)	• Assumes that others have pieces of the answer
• Attempts to prove the other side wrong	• Attempts to find common understanding
• Objective is to win	• Objective is to find common ground
• Listening to find flaws	• Listening to understand
• Defends personal assumptions	• Explores and tests personal assumptions
• Criticizes others' point of view	• Examines all points of view
• Defends one's views against others	• Admits that others' thinking can improve one's own
• Searches for weaknesses and flaws in the others' positions	• Searches for strengths and value in the others' positions
• Seeks an outcome that agrees with your position	• Seeks an outcome that creates new common ground

Ground Rules for Dialogue

The following ground rules can help us engage in good dialogue.

1. The purpose of dialogue is to understand and to learn from one another (you cannot "win" a dialogue).

2. All dialogue participants speak for themselves, not as a representative of others' interests.

3. In a dialogue, everyone is treated as an equal: leave status and stereotypes at the door.

4. Be open and listen to others especially when you disagree. Suspend judgment.

5. Identify and test assumptions (even your own).

6. Listen carefully and respectfully to the views of others: acknowledge you have heard the other, especially when you disagree.

7. Look for common ground.

8. Express disagreement with ideas, not with personalities or motives.

9. Respect all points of view.

10. Share the airtime – don't dominate the conversation.

An Overview Of The State of Vaccines and the US Immunization System - 2009

William Atkinson, MD, MPH
Centers for Disease Control and Prevention
Presentation to the Public Engagement Project on the National Vaccine Plan
Columbus, Ohio
March 28, 2009

Four Purposes Today

- Describe vaccines
- Describe the U.S. vaccination system
- Describe the accomplishments to date
- Describe the work that remains to be done

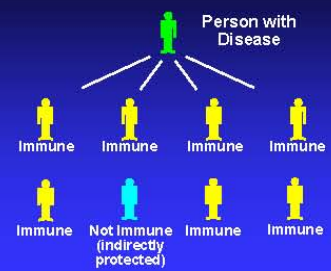
I. What Are Vaccines?

- Weakened or killed viruses or bacteria
- They prepare the body (the immune system) to fight off disease by making antibodies
- Antibodies are special proteins that neutralize or destroy the viruses or bacteria that cause disease
- Vaccines make the immune system STRONGER!

II. What Are Vaccines?

- Your body retains antibodies and can fight disease for many years
- This protection lasts longer for some vaccines than others
  - sometimes vaccination is needed again to keep protection
- Vaccinating many people also protects the few people who are not vaccinated—"community immunity"

Community ("herd") Immunity



I. Where Do Vaccines Come From?

- Researchers sponsored by agencies like the National Institutes of Health, Universities, and vaccine companies create vaccines by weakening or killing viruses or bacteria
- Researchers first test new vaccines in the laboratory, then in animals, then in small numbers of human volunteers

II. Where Do Vaccines Come From?

- Vaccines that produce antibodies and are safe are tested in larger groups of people
- Vaccines that protect people and are safe are licensed by the Food and Drug Administration (FDA)
- Only vaccines licensed by the FDA are available to the general population

Department of Health and Human Services

III. Where Do Vaccines Come From?

- Before licensure vaccines are tested in 10s of thousands of volunteers
- Even very large vaccine trials cannot identify side effects that are very rare
- Like all medicines, vaccines are never 100% safe or 100% effective
  - they are as safe as possible
  - serious reactions are rare

Department of Health and Human Services

IV. Where Do Vaccines Come From?

- Vaccine companies make licensed vaccines for sale in the US and abroad
- There is only a small number of companies that make vaccines today in the US
- To bring a vaccine to market—
  - at least $500 million
  - average more than 8 years of research and testing

Department of Health and Human Services

What Vaccines Do We Have Now?

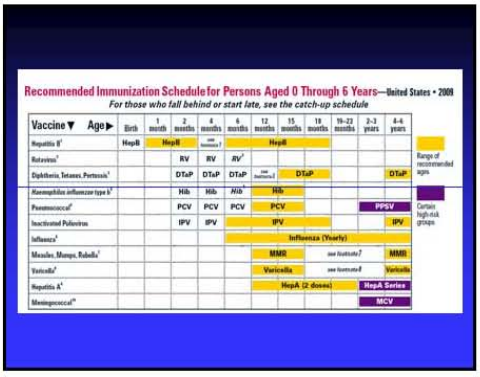
1985	1994	2009
Measles	Measles	Measles
Rubella	Rubella	Rubella
Mumps	Mumps	Mumps
Diphtheria	Diphtheria	Diphtheria
Tetanus	Tetanus	Tetanus
Pertussis	Pertussis	Pertussis
Polio	Polio	Polio
	Hib (infant)	Hib (infant)
	HepB	HepB
		Varicella
		Pneumococcal disease
		Influenza
		Meningococcal disease
		HepA
		Rotavirus
		HPV
7	9	16

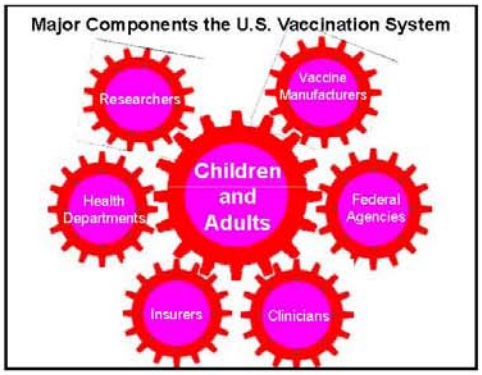
Department of Health and Human Services

Vaccine Recommendations-- What Vaccines Do We Need?

- Committee of experts advises the Centers for Disease Control and Prevention (CDC)
- CDC recommends a vaccination "schedule" to doctors
- Other doctor groups also make recommendations
- All groups work together to create the same schedules for children and adults

Department of Health and Human Services



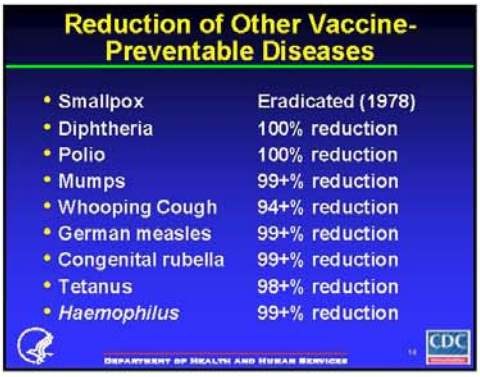

Major Components the U.S. Vaccination System
Researchers
Vaccine Manufacturers
Children and Adults
Health Departments
Federal Agencies
Insurers
Clinicians

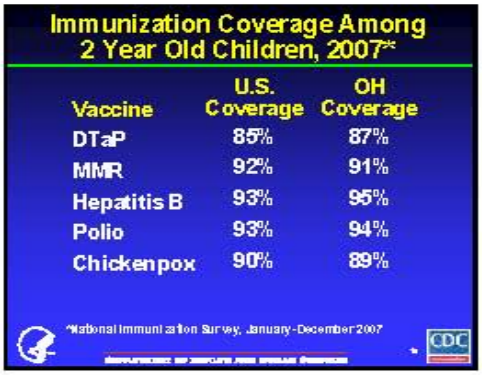

Helping Other Countries
(CDC, NIH, FDA, USAID)
• Support vaccine purchase and vaccination programs in poor countries
– Programs to fight disease, e.g. polio
– Programs to help vaccinate children
– Programs to help track disease
– Research
– Technical Assistance in Licensing Vaccines
Department of Health and Human Services
CDC

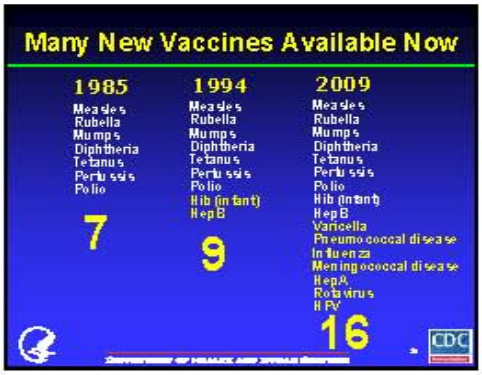

Accomplishments To Date
Department of Health and Human Services
CDC

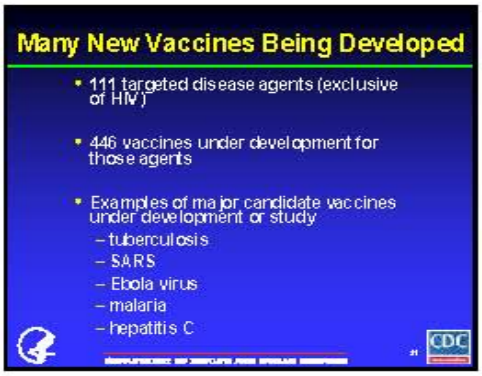

Smallpox


WORLD HEALTH
smallpox is dead!


Reduction of Other Vaccine-Preventable Diseases
• Smallpox Eradicated (1978)
• Diphtheria 100% reduction
• Polio 100% reduction
• Mumps 99+% reduction
• Whooping Cough 94+% reduction
• German measles 99+% reduction
• Congenital rubella 99+% reduction
• Tetanus 98+% reduction
• Haemophilus 99+% reduction
Department of Health and Human Services
CDC

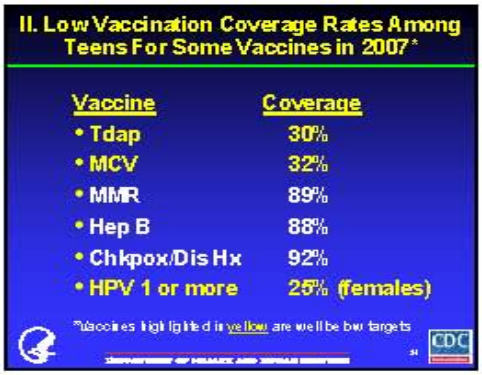

Immunization Coverage Among 2 Year Old Children, 2007*
Vaccine
U.S. Coverage
OH Coverage
DTaP
85%
87%
MMR
92%
91%
Hepatitis B
93%
95%
Polio
93%
94%
Chickenpox
90%
89%
*National Immunization Survey, January-December 2007
CDC


Many New Vaccines Available Now
1985
Measles
Rubella
Mumps
Diphtheria
Tetanus
Pertussis
Polio
7
1994
Measles
Rubella
Mumps
Diphtheria
Tetanus
Pertussis
Polio
Hib (infant)
HepB
9
2009
Measles
Rubella
Mumps
Diphtheria
Tetanus
Pertussis
Polio
Hib (infant)
HepB
Varicella
Pneumococcal disease
Influenza
Meningococcal disease
HepA
Rotavirus
HPV
16
CDC


Many New Vaccines Being Developed
• 111 targeted disease agents (exclusive of HIV)
• 446 vaccines under development for those agents
• Examples of major candidate vaccines under development or study
– tuberculosis
– SARS
– Ebola virus
– malaria
– hepatitis C
CDC


Remaining Challenges
CDC


I. Vaccine Shortages
• Vaccine shortages have occurred frequently in the past decade
• Some possible reasons
–Only 5 primary companies
–Limited profits from older vaccines
–Limited government stockpiles
–Stringent government regulations
CDC


II. Low Vaccination Coverage Rates Among Teens For Some Vaccines in 2007*
Vaccine
Coverage
• Tdap
30%
• MCV
32%
• MMR
89%
• Hep B
88%
• Chkpox/Dis Hx
92%
• HPV 1 or more
25% (females)
*Vaccines highlighted in yellow are well below targets
CDC

III. Low Vaccination Coverage Rates Among Adults Overall in 2007*

Vaccine	Coverage
• Influenza	37-69%
• Tdap	2%
• Tetanus (in 10y)	44-57%
• Pneumococcal	33-65%
• Shingles	1-2%
• Hep A	12%
• Hep B	23%
• HPV	1-10%

*All levels are below recommended or desired targets

IV. Cost of Vaccines

- Cost of vaccines for children and adolescents have increased dramatically
  - $45 in 1985
  - $155 in 1995
  - $1,105 in 2008 (males)
  - $1407 in 2008 (females)
- New $$ problems for patients, doctors, and health departments
  - Reimbursement issues
  - Paying for vaccinations in alternative sites
- 45 million persons have no health insurance

V. Vaccine Safety Concerns

- Increased publicity about possible vaccine safety problems, such as autism and vaccines
- More widespread concern in the population about vaccine safety

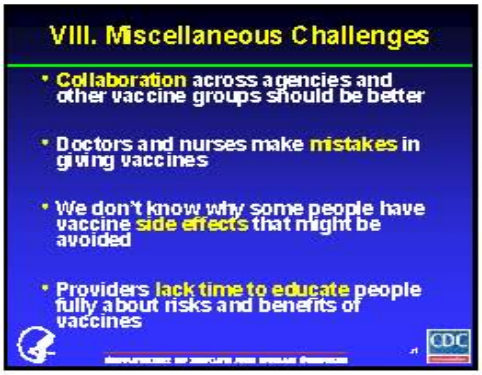
VI. Disease in Poor Countries

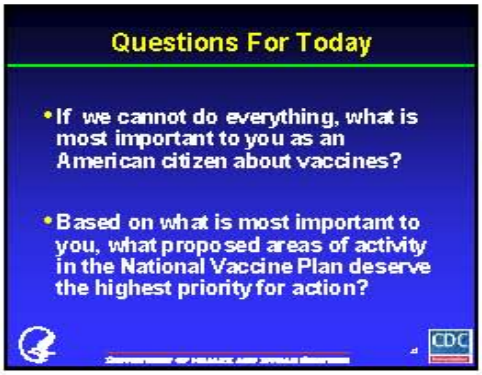
- No vaccines yet against global health threats such as HIV, TB, and malaria
- Many poor countries are not making use of existing vaccines

Polio in West Africa, 2004 Still Not Eradicated Worldwide in 2009

VII. Pandemic and Bioterrorist Threats

- We are not fully prepared to vaccinate against pandemic infections that might occur
- We are not fully prepared to vaccinate against bioterrorist threats that might occur


VIII. Miscellaneous Challenges
• Collaboration across agencies and other vaccine groups should be better
• Doctors and nurses make mistakes in giving vaccines
• We don't know why some people have vaccine side effects that might be avoided
• Providers lack time to educate people fully about risks and benefits of vaccines
CDC


Questions For Today
• If we cannot do everything, what is most important to you as an American citizen about vaccines?
• Based on what is most important to you, what proposed areas of activity in the National Vaccine Plan deserve the highest priority for action?
CDC


Draft National Vaccine Plan
12 Major Proposed Areas of Activity To Be Discussed Today
• Improve the information offered about vaccines
• Improve tools for making vaccines
• Improve vaccine safety
• Assure there are enough vaccines
• Make vaccine affordable and available to everyone
• Increase vaccination of adults
CDC


Draft National Vaccine Plan
12 Major Proposed Areas of Activity To Be Discussed Today
• Increase and/or maintain high rate of vaccination in children
• Develop new vaccines
• Improve monitoring of disease and vaccines
• Ensure compensation for those injured by vaccines
• Help other countries reduce diseases through vaccination
• Increase vaccination of adolescents
CDC

Public Values to Consider in Prioritizing National Vaccine Plan Activities

What Matters To Us	
1. Achieving Equity	• Make vaccines easily available and affordable for everyone in the U.S.
2. Protecting Our Homeland First	• Make sure people entering the U.S. are vaccinated, and American travelers are vaccinated before they leave the U.S.
3. Helping Other Countries	• Help poor countries to vaccinate their people. Help make vaccines for diseases common in other countries, but not in the U.S. (such as malaria).
4. Being Vigilant	• Measure how well existing vaccines are working in the U.S. and abroad. Work with others to identify new diseases in the world.
5. Assuring Fairness	• Compensate people injured by vaccines they were required to receive.
6. Emphasizing Safety	• Make vaccines even safer, even if it means that new ones take longer to develop or have to pass tougher tests.
7. Tackling Biggest Problems First	• Invest resources in new vaccines for common diseases, not rare ones.
8. Greater Protection Now	• Work to increase vaccination of teenagers and adults. Make better use of existing vaccines to protect more people.
9. Improving Our Science	• Increase research to better understand how vaccines work, and how they can be improved.
10. Promoting Education and Awareness	• Increase awareness of the benefits and risks of vaccines.
11. Securing Supply	• Improve our manufacturing and distribution systems to prevent shortages.
12. Protecting the Most Vulnerable	• Vaccinate persons who have increased risk for bad outcomes from disease, like the young, the old, and those with weak immune systems.
13. Protecting Individuals	• Conduct more research on why some persons have serious side effects and others do not.
14. Reduce Medical Costs	• Develop new vaccines that will help reduce the costs of treating illnesses.

Proposed Areas of Activity for the Draft National Vaccine Plan

1. Improve tools for making vaccines.
Improve ways to develop, make and test new vaccines.

2. Increase vaccination of adults.
Doctors suggest adults get vaccines for seasonal flu and other illnesses. Many adults don't get these vaccines.

3. Increase vaccination of adolescents.
Doctors suggest 9-18 year-olds get vaccines. These include vaccines against meningitis (swelling of the brain) and Human Papilloma Virus (HPV, a cause of cervical cancer). Vaccination rates are low.

4. Make vaccine affordable and available to everyone.
Help make vaccines available to those who cannot afford them. This includes people of all ages. It also includes groups with special needs such as those in nursing homes and others at high risk.

5. Maintain high rate of vaccination of children.
Doctors suggest children get vaccines against 14 diseases before two years old. Vaccination rates are high. The goal is to help ensure that they stay high.

6. Develop new vaccines.
Develop vaccines for such diseases as HIV/AIDS and malaria.

7. Assure there is enough vaccine.
Improve systems that manufacture and distribute vaccines. This is to help avoid shortages like the one that occurred with the flu shots several years ago.

8. Improve vaccine safety.
Learn more about the causes of side effects. Develop ways to predict who will have bad side effects. Improve ways to identify and respond to vaccine safety issues.

9. Assure compensation for those injured by vaccines.
Continue and improve the government system for compensation. The system identifies and pays money to people harmed by vaccines.

10. Help other countries reduce diseases through vaccination.
Help current programs such as those to get rid of polio and control measles. Help provide vaccines that the U.S. already has to countries that do not have them. Develop new vaccines for major health problems in other countries such as malaria.

11.Improve monitoring of disease and vaccines.
Measure vaccine success by counting the number of people getting vaccines and those still getting sick from the diseases the vaccines would prevent.

12. Improve the information offered about vaccines.
Improve the information offered about vaccine benefits and risks. This will help doctors, patients, and policy makers make decisions.

An Overview Of The Proposed Areas of Activity in the Draft National Vaccine Plan

Raymond A. Strikas, MD
Department of Health and Human Services
National Vaccine Program Office
Presentation to the Public Engagement Project on the National Vaccine Plan
Columbus, Ohio
March 28, 2009

2008 Draft Strategic National Vaccine Plan Goals

1. Develop new and improved vaccines
2. Enhance the safety of vaccines and vaccination practices
3. Support informed vaccine decision-making by the public, providers, and policy-makers
4. Ensure a stable supply of recommended vaccines and achieve better use of existing vaccines to prevent disease, disability and death in the United States
5. Increase global prevention of death and disease through safe and effective vaccination

1. Develop new vaccines

- Develop vaccines for such diseases as HIV/AIDS and malaria.
- Develop vaccines for potential pandemic diseases such as influenza
- Develop vaccines for potential bioterrorist threats

2. Improve Tools For Making Vaccines

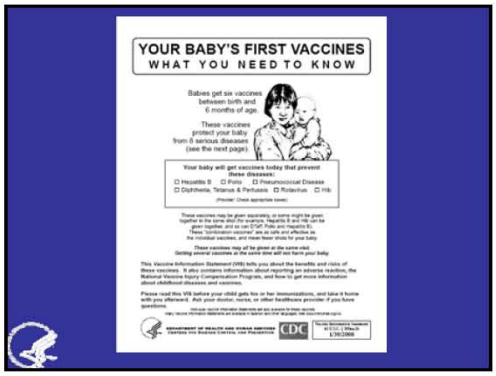
- Includes improving ways to:
  - Develop vaccines
  - Make vaccines
  - Test vaccines before licensure

3. Improve vaccine safety

- Learn more about the causes of side effects
- Develop ways to predict who will have bad side effects
- Improve ways to identify and respond to vaccine safety issues when they arise

4. Improve the information offered about vaccines

- Improve the information offered about vaccine benefits and risks to:
  - providers
  - parents and patients
  - the media
  - elected officials and policy makers



5. Assure there is enough vaccine

- Help avoid shortages such as the one which occurred with flu vaccine several years ago
- Improve systems that
  - Make vaccines
  - Distribute vaccines
- Assure adequate stockpiles of vaccine

6. Make vaccine affordable and available to everyone

- Help make vaccines available to those who cannot afford them
  - **People of all ages**
  - **Groups with special needs**
    - **Nursing home residents**
    - **Others at high risk**

7. Maintain high rate of vaccination of children

- Doctors suggest children get vaccines against 14 diseases before two years old.
- Vaccination rates are high.
- The goal is to help ensure that they stay high.

8. Increase vaccination of adults

- Doctors suggest adults get vaccines for seasonal flu and other illnesses
- Vaccination rates are below desired goal levels

9. Increase vaccination of adolescents

- Doctors suggest 9-18 year-olds get vaccines
  - meningitis (swelling of the brain)
  - Human Papilloma Virus (HPV, a cause of cervical cancer)
- Vaccination rates are low.

10. Assure compensation for those injured by vaccines

- Continue and improve the system for compensation
- The system identifies and pays money to people harmed by vaccines.

11. Improve monitoring of disease and vaccines

- Vaccine success is measured by the number of people getting the vaccine
- Also, measured by the number of people still getting sick.
- Evaluation is a necessary ingredient to determine where improvements are needed

12. Help other countries reduce diseases through vaccination

- Help current programs such as those to get rid of polio and control measles.
- Help provide vaccines that the U.S. already has to countries that do not have them.
- Develop new vaccines for major health problems in other countries such as malaria.

Stakeholder Process

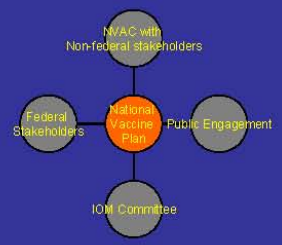


Table Activity

For each box, please assign a number that indicates how good the fit is between the value and the area of activity for your group . Use the following scale:

5 for a strong fit

3 for a medium fit

1 for a weak fit

The total provides the overall goodness of fit between the values and the areas of activity.

Each proposed area of activity must obtain a total score between 0-20 pts.

Proceed by selecting one value at a time and examining each of the 12 proposed areas of activity against that value.

Repeat the process of examining all 12 proposed areas of activity for each value identified.

Area of Activity	*Value* _____	*Value* _____	*Value* _____	*Value* _____	*TOTAL Score*
1. Improve tools for making vaccines.					
2. Increase vaccination of adults.					
3. Increase vaccination of adolescents.					
4. Make vaccine affordable and available to everyone.					
5. Maintain high rate of vaccination of children.					
6. Develop new vaccines.					
7. Assure there is enough vaccine.					
8. Improve vaccine safety.					
9. Assure compensation for those injured by vaccines.					
10. Help other countries reduce diseases through vaccination.					
11. Improve monitoring of disease and vaccines.					
12. Improve the information offered about vaccines.					

Example Table – Choosing a Vacation Destination

5 for a strong fit

3 for a medium fit

1 for a weak fit

Destinations	*Value* Entertainment	*Value* History	*Value* Nature	**TOTAL**
Las Vegas	5	1	1	7
Boston	5	5	1	11
Glacier National Park	1	1	5	7
Grand Canyon	3	1	5	9

Websites for More Information About Vaccines

American Academy of Pediatrics – Childhood Immunization Support Program: www.cispimmunize.org

Centers for Disease Control and Prevention – Vaccines & Immunizations: www.cdc.gov/vaccines

Centers for Disease Control and Prevention – Traveler's Health: www.cdc.gov/travel

Every Child By Two: www.ecbt.org

Food and Drug Administration - Vaccines: www.fda.gov/cber/vaccines.htm

Health Resources and Services Administration – National Vaccine Injury Compensation Program: www.hrsa.gov/vaccinecompensation

Immunization Action Coalition (IAC): www.immunize.org

National Institutes of Health – Immunization/Vaccination: www.health.nih.gov/topic/ImmunizationVaccination

The Children's Hospital of Philadelphia – Vaccine Education Center: www.vaccine.chop.edu

Glossary of Common Terms related to Vaccines and Immunization Programs

(Adapted from the Glossary available at http://www.cdc.gov/vaccines/about/terms/glossary.htm)

A

Acellular vaccine: A vaccine containing partial cellular material as opposed to complete cells.

Acquired Immune Deficiency Syndrome (AIDS): A medical condition where the immune system cannot function properly and protect the body from disease. As a result, the body cannot defend itself against infections (like pneumonia). AIDS is caused by the Human Immunodeficiency Virus (HIV). This virus is spread through direct contact with the blood and body fluids of an infected individual. High risk activities include unprotected sexual intercourse and intravenous drug use (sharing needles). There is no cure for AIDS, however, research efforts are on-going to develop a vaccine.

Active immunity: The production of antibodies against a specific disease by the immune system. Active immunity can be acquired in two ways, either by contracting the disease or through vaccination. Active immunity is usually permanent, meaning an individual is protected from the disease for the duration of their lives.

Acute: A short-term, intense health effect.

Adjuvant: A substance (e.g. aluminum salt) that is added during production to increase the body's immune response to a vaccine.

Adverse events: Undesirable experiences occurring after immunization that may or may not be related to the vaccine.

Advisory Commission on Childhood Vaccines (ACCV): There are nine voting members who provide oversight of the National Vaccine Injury Compensation Program (VICP) and recommend ways to improve the VICP. The ACCV advises and makes recommendations to the Secretary of Health and Human Services on issues relating to the operation of the (VICP).

Advisory Committee on Immunization Practices (ACIP): A panel of 10 experts who make recommendations on the use of vaccines in the United States. The panel is advised on current issues by representatives from the Centers for Disease Control and Prevention, Food and Drug Administration, National Institutes of Health, American Academy of Pediatrics, American Academy of Family Physicians, American Medical Association and others. The recommendations of the ACIP guide immunization practice at the federal, state and local level.

Allergy: A condition in which the body has an exaggerated response to a substance (e.g. food or drug). Also known as hypersensitivity.

Anaphylaxis: An immediate and severe allergic reaction to a substance (e.g. food or drugs). Symptoms of anaphylaxis include breathing difficulties, loss of consciousness and a drop in blood pressure. This condition can be fatal and requires immediate medical attention.

Anthrax: An acute infectious disease caused by the spore-forming bacterium *Bacillus anthracis*. Anthrax most commonly occurs in hoofed mammals and can also infect humans.

Antibiotic: A substance that fights bacteria.

Antibody: A protein found in the blood that is produced in response to foreign substances (e.g. bacteria or viruses) invading the body. Antibodies protect the body from disease by binding to these organisms and destroying them.

Antigens: Foreign substances (e.g. bacteria or viruses) in the body that are capable of causing disease. The presence of antigens in the body triggers an immune response, usually the production of antibodies.

Antitoxin: Antibodies capable of destroying microorganisms including viruses and bacteria.

Antiviral: Literally "against-virus" -- any medicine capable of destroying or weakening a virus.

Association: The degree to which the occurrence of two variables or events is linked. Association describes a situation where the likelihood of one event occurring depends on the presence of another event or variable. However, an association between two variables does not necessarily imply a cause and effect relationship. The term association and relationship are often used interchangeably. See causal and temporal association.

Asthma: A chronic medical condition where the bronchial tubes (in the lungs) become easily irritated. This leads to constriction of the airways resulting in wheezing, coughing, difficulty breathing and production of thick mucus. The cause of asthma is not yet known but environmental triggers, drugs, food allergies, exercise, infection and stress have all been implicated.

Asymptomatic infection: The presence of an infection without symptoms. Also known as inapparent or subclinical infection.

Attenuated vaccine: A vaccine in which live virus is weakened through chemical or physical processes in order to produce an immune response without causing the severe effects of the disease. Attenuated vaccines currently licensed in the United States include measles, mumps, rubella, polio, yellow fever and varicella. Also known as a live vaccine.

Autism: A chronic developmental disorder usually diagnosed between 18 and 30 months of age. Symptoms include problems with social interaction and communication as well as repetitive interests and activities. At this time, the cause of autism is not known although many experts believe it to be a genetically based disorder that occurs before birth.

B

B cells: Small white blood cells that help the body defend itself against infection. These cells are produced in bone marrow and develop into plasma cells which produce antibodies. Also known as B lymphocytes.

Bacteria: Tiny one-celled organisms present throughout the environment that require a microscope to be seen. While not all bacteria are harmful, some cause disease. Examples of bacterial disease include diphtheria, pertussis, tetanus, Haemophilus influenza and pneumococcus (pneumonia).

Bias: Flaws in the collection, analysis or interpretation of research data that lead to incorrect conclusions.

Biological plausibility: A causal association (or relationship between two factors) is consistent with existing medical knowledge.

Booster shots: Additional doses of a vaccine needed periodically to "boost" the immune system. For example, the tetanus and diphtheria (Td) vaccine which is recommended for adults every ten years.

Breakthrough infection: Development of a disease despite a person's having responded to a vaccine.

C

Causal association: The presence or absence of a variable (e.g. smoking) is responsible for an increase or decrease in another variable (e.g. cancer). A change in exposure leads to a change in the outcome of interest.

Chronic health condition: A health related state that lasts for a long period of time (e.g. cancer, asthma).

Communicable: That which can be transmitted from one person or animal to another.

Combination vaccine: Two or more vaccines administered at once in order to reduce the number of shots given. For example, the MMR (measles, mumps, rubella) vaccine.

Communicable: Capable of spreading disease. Also known as infectious.

Community immunity: Having a large percentage of the population vaccinated in order to prevent the spread of certain infectious diseases. Even individuals not vaccinated (such as newborns and those with chronic illnesses) are offered some protection because the disease has little opportunity to spread within the community. Also known as herd immunity.

Conjugate vaccine: The joining together of two compounds (usually a protein and polysaccharide) to increase a vaccine's effectiveness.

Contraindication: A condition in a recipient which is likely to result in a life-threatening problem if a vaccine were given.

Convulsion: See Seizure.

Crib or Cot Death: See Sudden Infant Death Syndrome (SIDS).

D

Deltoid: A muscle in the upper arm where shots are usually given.

Demyelinating disorders: A medical condition where the myelin sheath is damaged. The myelin sheath surrounds nerves and is responsible for the transmission of impulses to the brain. Damage to the myelin sheath results in muscle weakness, poor coordination and possible paralysis. Examples of demyelinating disorders include Multiple Sclerosis (MS), optic neuritis, transverse neuritis and Guillain-Barre Syndrome (GBS).

Diabetes: A chronic health condition where the body is unable to produce insulin and properly breakdown sugar (glucose) in the blood. Symptoms include hunger, thirst, excessive urination, dehydration and weight

loss. The treatment of diabetes requires daily insulin injections, proper nutrition and regular exercise. Complications can include heart disease, stroke, neuropathy, poor circulation leading to loss of limbs, hearing impairment, vision problems and death.

Diphtheria: A bacterial disease marked by the formation of a false membrane, especially in the throat, which can cause death.

Disease: Sickness, illness or loss of health.

E

Efficacy rate: A measure used to describe how good a vaccine is at preventing disease.

Encephalitis: Inflammation of the brain caused by a virus. Encephalitis can result in permanent brain damage or death.

Encephalopathy: A general term describing brain dysfunction. Examples include encephalitis, meningitis, seizures and head trauma.

Epidemic: The occurrence of disease within a specific geographical area or population that is in excess of what is normally expected.

Endemic: The continual, low-level presence of disease in a community

Etiology: The cause of.

Exposure: Contact with infectious agents (bacteria or viruses) in a manner that promotes transmission and increases the likelihood of disease.

F

Febrile: Relating to fever; feverish.

G

Guillain-Barre Syndrome (GBS): A rare neurological disease characterized by loss of reflexes and temporary paralysis. Symptoms include weakness, numbness, tingling and increased sensitivity that spreads over the body. Muscle paralysis starts in the feet and legs and moves upwards to the arms and hands. Sometimes paralysis can result in the respiratory muscles causing breathing difficulties. Symptoms usually appear over the course of one day and may continue to progress for 3 or 4 days up to 3 or 4 weeks. Recovery begins within 2-4 weeks after the progression stops. While most patients recover, approximately 15%-20% experience persistent symptoms. GBS is fatal in 5% of cases.

H

***Haemophilus influenzae* type b (Hib):** A bacterial infection that may result in severe respiratory infections, including pneumonia, and other diseases such as meningitis.

Hepatitis A: A minor viral disease, that usually does not persist in the blood; transmitted through ingestion of contaminated food or water.

Hepatitis B: A viral disease transmitted by infected blood or blood products, or through unprotected sex with someone who is infected.

Herd immunity: See Community immunity.

Herpes Zoster: A disease characterized by painful skin lesions that occur mainly on the trunk (back and stomach) of the body but which can also develop on the face and in the mouth. Complications include headache, vomiting, fever and meningitis. Recovery may take up to 5 weeks. Herpes Zoster is caused by the same virus that is responsible for chickenpox. Most people are exposed to this virus during childhood. After the primary infection (chickenpox), the virus becomes dormant, or inactivated. In some people the virus reactivates years, or even decades, later and causes herpes zoster. Also known as the shingles.

Hives: The eruption of red marks on the skin that are usually accompanied by itching. This condition can be caused by an allergy (e.g. to food or drugs), stress, infection or physical agents (e.g. heat or cold). Also known as uticaria.

Hypersensitivity: A condition in which the body has an exaggerated response to a substance (e.g. food or drug). Also known as an allergy.

Hyposensitivity: A condition in which the body has a weakened or delayed reaction to a substance.

I

Immune globulin: A protein found in the blood that fights infection. Also known as gamma globulin.

Immune system: The complex system in the body responsible for fighting disease. Its primary function is to identify foreign substances in the body (bacteria, viruses, fungi or parasites) and develop a defense against them. This defense is known as the immune response. It involves production of protein molecules called antibodies to eliminate foreign organisms that invade the body.

Immunity: Protection against a disease. There are two types of immunity, passive and active. Immunity is indicated by the presence of antibodies in the blood and can usually be determined with a laboratory test. See active and passive immunity.

Immunization: The process by which a person or animal becomes protected against a disease. This term is often used interchangeably with vaccination or inoculation.

Immunosupression: When the immune system is unable to protect the body from disease. This condition can be caused by disease (like HIV infection or cancer) or by certain drugs (like those used in

chemotherapy). Individuals whose immune systems are compromised should not receive live, attenuated vaccines.

Inactive vaccine: A vaccine made from viruses and bacteria that have been killed through physical or chemical processes. These killed organisms cannot cause disease.

Inapparent infection: The presence of infection without symptoms. Also known as subclinical or asymptomatic infection.

Incidence: The number of new disease cases reported in a population over a certain period of time.

Incubation period: The time from contact with infectious agents (bacteria or viruses) to onset of disease.

Infectious: Capable of spreading disease. Also known as communicable.

Infectious agents: Organisms capable of spreading disease (e.g. bacteria or viruses).

Inflammation: Redness, swelling, heat and pain resulting from injury to tissue (parts of the body underneath the skin). Also known as swelling.

Influenza: A highly contagious viral infection characterized by sudden onset of fever, severe aches and pains, and inflammation of the mucous membrane.

Investigational vaccine: A vaccine that has been approved by the Food and Drug Administration (FDA) for use in clinical trials on humans. However, investigational vaccines are still in the testing and evaluation phase and are not licensed for use in the general public.

J

Jaundice: Yellowing of the eyes. This condition is often a symptom of hepatitis infection.

L

Lesion: An abnormal change in the structure of an organ, due to injury or disease.

Live vaccine: A vaccine in which live virus is weakened through chemical or physical processes in order to produce an immune response without causing the severe effects of the disease. Attenuated vaccines currently licensed in the United States include measles, mumps, rubella, polio, yellow fever and varicella. Also known as an attenuated vaccine.

Lyme disease: A bacterial disease transmitted by infected ticks. Human beings may come into contact with infected ticks during outdoor activities (camping, hiking). Symptoms include fatigue, chills, fever, headache, joint and muscle pain, swollen lymph nodes and a skin rash (in a circular pattern). Long-term problems include arthritis, nervous system abnormalities, irregular heart rhythm and meningitis. Lyme disease can be treated with antibiotics. A vaccine was available from 1998 to 2002.

Lymphocytes: Small white blood cells that help the body defend itself against infection. These cells are produced in bone marrow and develop into plasma cells which produce antibodies. Also known as B cells.

M

Macrophage: A large cell that helps the body defend itself against disease by surrounding and destroying foreign organisms (viruses or bacteria).

Macular: Skin lesions, normally red-colored.

Measles: A contagious viral disease marked by the eruption of red circular spots on the skin.

Memory Cell: A group of cells that help the body defend itself against disease by remembering prior exposure to specific organisms (e.g. viruses or bacteria). Therefore these cells are able to respond quickly when these organisms repeatedly threaten the body.

Meningitis: Inflammation of the brain and spinal cord that can result in permanent brain damage and death.

Meningoenephalitis: ["men in joe en sef uh LIGHT iss"] -- inflammation of the brain and meninges (membranes) that involves the encephalon (area inside the skull) and spinal column.

Microbes: Tiny organisms (including viruses and bacteria) that can only be seen with a microscope.

Mucosal membranes: The soft, wet tissue that lines body openings specifically the mouth, nose, rectum and vagina.

Mumps: Acute contagious viral illness marked by swelling, especially of the parotid glands.

N

National Vaccine Advisory Committee (NVAC): A panel of 17 experts who make recommendations about the U.S. immunization program to the Director of the National Vaccine Program, the Assistant Secretary for Health in the Department of Health and Human Services. The panel is advised on current issues by representatives from the Centers for Disease Control and Prevention, Centers for Medicare and Medicaid Services, Food and Drug Administration, National Institutes of Health, Health and Resources Services Administration, U.S. Agency for International Development, the Department of Defense, and the Department of Veterans Affairs.

National Vaccine Injury Compensation Program (VICP): The VICP was established to ensure an adequate supply of vaccines, stabilize vaccine costs, and establish and maintain an accessible and efficient forum for individuals found to be injured by certain vaccines. The VICP is a no-fault alternative to the traditional tort system for resolving vaccine injury claims that provides compensation to people found to be injured by certain vaccines. The U. S. Court of Federal Claims decides who will be paid. Three Federal government offices have a role in the VICP:

the U.S. Department of Health and Human Services (HHS);

the U.S. Department of Justice (DOJ); and

the U.S. Court of Federal Claims (the Court).

The VICP is located in the HHS, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Vaccine Injury Compensation.

Neuritis: Inflammation of the nerves.

Neuropathy: A general term for any dysfunction in the peripheral nervous system. Symptoms include pain, muscle weakness, numbness, loss of coordination and paralysis. This condition may result in permanent disability.

O

Optic neuritis: A medical condition where vision deteriorates rapidly over hours or days. One or both eyes may be affected. This condition results for the demyelination of optic nerves. In most cases, the cause of optic neuritis is unknown. Patients may regain their vision or be left with permanent impairment. Also see demyelinating disorders.

Orchitis: A complication of mumps infection occurring in males (who are beyond puberty). Symptoms begin 7-10 days after onset of mumps and include inflammation of the testicles, headache, nausea, vomiting, pain and fever. Most patients recover but in rare cases sterility occurs.

Otitis Media: A viral or bacterial infection that leads to inflammation of the middle ear. This condition usually occurs along with an upper respiratory infection. Symptoms include earache, high fever, nausea, vomiting and diarrhea. In addition, hearing loss, facial paralysis and meningitis may result.

Outbreak: Sudden appearance of a disease in a specific geographic area (e.g. neighborhood or community) or population (e.g. adolescents).

P

Pandemic: An epidemic occurring over a very large area.

Papular: Marked by small red-colored elevation of the skin.

Passive immunity: Protection against disease through antibodies produced by another human being or animal. Passive immunity is effective, but protection is generally limited and diminishes over time (usually a few weeks or months). For example, maternal antibodies are passed to the infant prior to birth. These antibodies temporarily protect the baby for the first 4-6 months of life.

Pathogens: Organisms (e.g. bacteria, viruses, parasites and fungi) that cause disease in human beings.

Pertussis: (whooping cough) Bacterial infectious disease marked by a convulsive spasmodic cough, sometimes followed by a crowing intake of breath.

Placebo: A substance or treatment that has no effect on human beings.

Pneumococcal disease: caused by the bacteria *Streptococcus pneumoniae*, and it causes pneumonia, blood infections, ear infections, otitis media, meningitis, and sinus infections. There are two vaccines available to prevent these infections, one for children and one primarily for adults.

Pneumonia: Inflammation of the lungs characterized by fever, chills, muscle stiffness, chest pain, cough, shortness of breath, rapid heart rate and difficulty breathing.

Poliomyelitis: (polio) An acute infectious viral disease characterized by fever, paralysis, and atrophy of skeletal muscles.

Polysaccharide vaccines: Vaccines that are composed of long chains of sugar molecules that resemble the surface of certain types of bacteria. Polysaccharide vaccines are available for pneumococcal disease, meningococcal disease and *Haemophilus Influenzae* type b.

Potency: A measure of strength.

Precaution: A condition in a recipient which may result in a life-threatening problem if the vaccine is given, or a condition which could compromise the ability of the vaccine to produce immunity.

Prevalence: The number of disease cases (new and existing) within a population over a given time period.

Prodromal: An early symptom indicating the onset of an attack or a disease.

Q

Quarantine: The isolation of a person or animal who has a disease (or is suspected of having a disease) in order to prevent further spread of the disease.

R

Recombinant: Of or resulting from new combinations of genetic material or cells; the genetic material produced when segments of DNA from different sources are joined to produce recombinant DNA.

Risk: The likelihood that an individual will experience a certain event.

Rotavirus: A group of viruses that cause diarrhea in children.

Rubella: (German measles) Viral infection that is milder than normal measles but as damaging to the fetus when it occurs early in pregnancy.

Rubeola: See Measles.

S

Seroconversion Development of antibodies in the blood of an individual who previously did not have detectable antibodies.

Serology: Measurement of antibodies, and other immunological properties, in the blood serum.

Serosurvey: Study measuring a person's risk of developing a particular disease.

Seizure: The sudden onset of a jerking and staring spell usually caused by fever. Also known as convulsions.

Shingles: See herpes zoster.

Side Effect: Undesirable reaction resulting from immunization.

Smallpox: An acute, highly infectious, often fatal disease caused by a poxvirus and characterized by high fever and aches with subsequent widespread eruption of pimples that blister, produce pus, and form pockmarks. Also called variola.

Strain: A specific version of an organism. Many diseases, including HIV/AIDS and hepatitis, have multiple strains.

Subclinical infection: The presence of infection without symptoms. Also known as inapparent or asymptomatic infection.

Sudden Infant Death Syndrome (SIDS): The sudden and unexpected death of a healthy infant under 1 year of age. A diagnosis of SIDS is made when an autopsy cannot determine another cause of death. The cause of SIDS is unknown. Also known as "crib" or "cot" death.

Susceptible: Unprotected against disease.

T

Temporal association: Two or more events that occur around the same time but are unrelated, chance occurrences.

Teratogenic: Of, relating to, or causing developmental malformations.

Tetanus: Toxin-producing bacterial disease marked by painful muscle spasms.

Thimerosal: Thimerosal is a mercury-containing preservative that has been used in some vaccines and other products since the 1930's. There is no evidence that the low concentrations of thimerosal in vaccines have caused any harm other than minor reactions like redness or swelling at the injection site. However, in July 1999 the U.S. Public Health Service, the American Academy of Pediatrics, and vaccine manufacturers agreed that thimerosal should be reduced or eliminated from vaccines as a precautionary measure. Today, all routinely recommended childhood vaccines manufactured for the U.S. market contain either no thimerosal or only trace amounts.

Titer: The detection of antibodies in blood through a laboratory test.

Transverse Myelitis: The sudden onset of spinal cord disease. Symptoms include general back pain followed by weakness in the feet and legs that moves upward. There is no cure and many patients are left with permanent disabilities or paralysis. Transverse Myelitis is a demyelinating disorder that may be associated with Multiple Sclerosis (MS). Also see demyelinating disorders.

U

Urticaria: The eruption of red marks on the skin that are usually accompanied by itching. This condition can be caused by an allergy (e.g. to food or drugs), stress, infection or physical agents (e.g. heat or cold). Also known as hives.

V

Vaccination: Injection of a killed or weakened infectious organism in order to prevent the disease.

Vaccine: A product that produces immunity therefore protecting the body from the disease. Vaccines are administered through needle injections, by mouth and by aerosol.

Vaccine Adverse Event Reporting System (VAERS): A database managed by the Centers for Disease Control and Prevention and the Food and Drug Administration. VAERS provides a mechanism for the collection and analysis of adverse events associated with vaccines currently licensed in the United States. Reports to VAERS can be made by the vaccine manufacturer, recipient, their parent/guardian or health care provider. For more information on VAERS call (800) 822-7967.

Vaccine Safety Datalink Project (VSD): In order to increase knowledge about vaccine adverse events, the Centers for Disease Control and Prevention have formed partnerships with eight large health Management Organizations (HMOs) to continually evaluate vaccine safety. The project contains data on more than 6 million people. Medical records are monitored for potential adverse events following immunization. The VSD project allows for planned vaccine safety studies as well as timely investigations of hypothesis.

Varicella: (Chickenpox) -- An acute contagious disease characterized by papular and vesicular lesions.

Variola: See smallpox.

Vesicular: Characterized by small elevations of the skin containing fluid (blisters).

Viremia: The presence of a virus in the blood.

Virulence: The relative capacity of a pathogen to overcome body defenses.

Virus: A tiny organism that multiplies within cells and causes disease such as chickenpox, measles, mumps, rubella, pertussis and hepatitis. Viruses are not affected by antibiotics, the drugs used to kill bacteria.

W

Waning Immunity: The loss of protective antibodies over time.

Whooping Cough: See Pertussis.

Acknowledgements and Contact for More Information

The National Vaccine Plan Dialogue was sponsored by:
U.S. Department of Health and Human Services

Technical assistance was provided by:
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Columbus Public Health
The Ohio State University College of Public Health

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Appendix E. Participant Information Sheet

U. S. Department of Health and Human Services

Deliberation Days: Public Values in National Vaccine Planning

Information for Participants

Purpose of this survey

You are being asked to participate in a Deliberation Day being done by the U.S. Department of Health and Human Services, with the assistance of The Oak Ridge Institute for Science and Education. In the discussion, asked to participate in discussions about possible goals in national vaccine planning. Your answers can help in improving the National Vaccine Plan.

Please remember that:

You choose to participate.
You are not required to answer any particular question.
This session should end by 4:30 p.m.
You will receive an incentive for participating in the discussion.
You are free to leave at any time without losing the incentive or other penalty.

Risks

The risks you take by taking part in the discussion are the same as you encounter in daily life.

Benefits

You will be better informed about a public health issue.
You may have a sense of satisfaction from contributing.
Your comments may help in developing a better national plan.
You will receive an incentive for participating in the discussion.

Confidentiality

We will keep the information you give us private and confidential to the extent allowed by law. Your name will not be used in the final report. No statement you make will be linked to you by name. Only members of the project staff will be allowed to look at the records. When we present this study or publish its results, your name or other facts that point to you will not show or be used.

Persons to Contact

If you have questions about this session, or taking part in it, you may talk with one of the representatives of the US Department of Health and Human Services here today. After the event, you may call Dr. Raymond Strikas, National Vaccine Program Office, Washington, DC, 202-260-2652

If you need more information about your rights as a study participant, you may contact: Chair, Oak Ridge Site-Wide Institutional Review Board, Oak Ridge Institute for Science and Education, Oak Ridge, TN 37831-0117, 865- 576-1725.

Appendix F. Additional Findings

F-1. Interests About Vaccines and Reasons for Participation

According to data recorded by note takers during small-group discussion, the majority of participants attended the National Vaccine Plan dialogue for one of four reasons: (1) the desire to gain knowledge about vaccines and the National Vaccine Program, (2) concern about vaccines and vaccine safety, (3) the desire to have a voice in vaccine and health care planning, and (4) interest in the topic of vaccines (see table F-1).

Table F-1. Why Did Participants Come?

Why did participants come?	Number of work sheet references*
Desire to gain knowledge about vaccines and program	66
Concern about vaccines and vaccine safety	26
Desire to have a voice	20
Interest in topic	19
Anti-vaccine beliefs of self/family/friend	12
Civil duty	11
Monetary incentive	10
Child of self/family/friend with autism	9
Previous vaccine experiences	8

**Refers to work sheet data recorded by note takers during small-group discussion.*

Desire to gain knowledge about vaccines and program
Participants came to listen and learn. Participants in particular wanted to learn about new vaccines, the immunization schedule, and the number of recommended vaccines. They were motivated to do so for their family and for their health care or teaching profession. Some were interested in learning about how to better evaluate certain vaccines due to a desire to vaccinate their children less and either financial constraints or safety concerns.

Concern about vaccines and vaccine safety
The second most frequently cited reason for attendance was related to concerns about vaccines and vaccine safety. Concerns were related to an association between vaccines and autism, a lack of effectiveness due to "immunity buildup," side effects, contaminated vaccines, number of doses in the vaccine schedule, and an association between vaccines and cancer. The majority of comments were related to concern for safety of children, but some implied concern for safety of all ages. Some participants shared concerns about vaccine research, the manufacturing process, and a lack of informed choice.

Desire to have a voice
Many participants in attendance desired a voice in vaccine and health care planning and policy. Some attended in support of vaccines, while other attended to voice concerns about vaccines. Some participants desired a change in the current immunization system, while others desired a more comprehensive change to the health care system. Many voiced concerns about children and seniors, while others were concerned for the global community and availability and affordability of vaccines in other countries.

Interest about topic

Another top motivator for attendance was general interest in the topic of vaccines. Some had specific interests in vaccine shortages and availability of free vaccinations for children. Interests were generally motivated by current or previous work in a health care or education profession or individual's family. Participants expressed a desire to help, learn about, or be involved in the community.

Table F-2 shows a summary of participant interest quotes.

Table F-2. Participant Interest Quotes

Desire to gain knowledge about vaccines and program

"Want to know the new vaccine plan, what will change, and how the plan will differ in other countries." (St. Louis)

"Young kids … how to evaluate what vaccines to receive with limited funds." (Columbus)

"Work with children … parents unaware of issues surrounding vaccines." (Columbus)

"I'm here because I'm a mom … and I'm not sure I asked them the right questions." (Syracuse)

"People need to be informed of where vaccines are made, what goes into them, and what the effects are." (Syracuse)

Concern about vaccines and vaccine safety

"Concern with impact of vaccines on our children … there are risks." (St. Louis)

"Worried about children being up to date on vaccines and the lack of education on the subject." (St. Louis)

"To allay personal concerns about safety of vaccines." (Columbus)

"Concerned about kids, grandkids safety. This will help . . . learn more to protect them." (Columbus)

"Concerned about the science behind the research of vaccines." (Syracuse)

"I'm concerned about our rights; we are being told that we have to have these done …." (Syracuse)

Desire to have a voice

"Need to be change with the current immunization system." (St. Louis)

"Wants vaccines to be available to those in countries where they aren't affordable." (St. Louis)

"All kids should be vaccinated for free; health system 'messed up' and wanted to have input." (Columbus)

"President speaking out and we need to also. We all need to … help impact decisions." (Columbus)

"I want to have my thoughts heard, but I don't think it will make a difference." (Syracuse)

Interest in topic

"Here because immunization is important for health of youth." (St. Louis)

""Interested in what I can learn." (Columbus)

"Interested in community and the topic and wants to know more."(Syracuse)

F-2. New Value Cards Created

Participants were invited to create additional value cards for the activity based on the Q methodology if they found that the pre-identified set of value cards was not sufficient. Table F-3 provides the new values generated and number of table groups across all three cities that created a value card related to that topic. All but ethics were values proposed by participants for consideration as a top value but ultimately not voted on as one that mattered most. Ethics was a value generated separately by one of the Syracuse small groups. After being presented in plenary session, ethics was voted as one of the top four priority values in Syracuse. However, ultimately, the value was determined to be an overarching theme that should permeate the entire spectrum of the NVP and was therefore not chosen as a criterion for selecting priority NVP activity areas.

Table F-3. New Value Cards Created

New value card created	Number of tables (n = 33)
Choice	5
Ethics	3
Importance of vaccines	1
Consumer engagement at federal level	1
Natural and alternative medicine	1

F-3. Top Values in Table Vote

Percentage of tables that voted for a value as one of their top four or five are reported in Table F-4. In general, tables voted for the same top values as individuals reported in table 6. Achieving equity was the most frequently cited value in all three cities and the only value voted one of the top four (or five) priorities in all three cities. Four other values were paramount in two out of three cities, including emphasizing safety, promoting education and awareness, protecting our homeland, and protecting the most vulnerable. Two other values were among the most frequently cited in a single city, reducing medical cost and improving our science. Altogether, five values were judged paramount in two or more cities.

Table F-4. Top Values in Table Vote

	St. Louis (n = 11)	Columbus (n = 13)	Syracuse (n = 9)
Achieving Equity	82%	69%	56%
Emphasizing Safety	55%	23%	67%
Promoting Education and Awareness	55%	31%	67%
Protecting Our Homeland	45%	85%	0%
Protecting the Most Vulnerable	36%	62%	33%
Reducing Medical Costs	9%	54%	11%
Improving Our Science	18%	8%	44%
Securing Supply	18%	23%	22%
Tackling Biggest Problems First	18%	15%	0%
Obtaining Greater Protection Now	9%	15%	22%
Helping Other Countries	18%	0%	22%
Being Vigilant	18%	8%	22%
Protecting Individuals	9%	8%	22%
Assuring Fairness	9%	0%	0%

F-4. Reflections on Pros, Cons, and Trade-offs of Other Proposed top Values

After voting once individually on top values, participants were asked to make a case for other values not in the top four. Below are reflections on the pros, cons, and trade-offs of these other proposed values.

In St. Louis, participants discussed the potential for adverse affects on the efficacy and safety of vaccines as a potential trade-off and con for cost restrictions and the resulting affordability of vaccines. A con or trade-off of helping other countries was that the protection of homeland may be compromised. Some participants suggested U.S. protection should be a priority, especially when funds are limited, while others felt that "protecting our homeland first and protecting others can go hand in hand [and] by keeping others [vaccinated] we are protecting ourselves."

In Columbus, participants expressed similar viewpoints, prioritizing that U.S. citizens should be helped first but acknowledging that helping other countries would also help protect the U.S. Participants saw promoting education and awareness as a potential to waste resources and be a con if other parts of the system such as supply were not already in place. Similarly, participants cited a potential con to securing supply without consideration to affordability and availability; securing supply was associated with achieving equity as well as protecting the most vulnerable. Securing supply was described as a pro for reducing manufacturing cost and increasing affordability of vaccines. A trade-off and con of focusing on assuring availability and affordability of vaccines to vulnerable populations was the potential to overlook a need for adult and teen protection. A pro of new vaccine development for common disorders was a reduction of overall medical costs.

In Syracuse, participants cited a pro of increased vaccination rates as reduced health care costs ("poor vaccination rates can cause overall health care costs to snowball"). Achieving equity was cited as a pro of securing supply ("because we don't have to make choices about who gets vaccines and [who] doesn't").

F-5. Best Activity-Value Fits (After Table Vote)

In all three cities, tables voted on the same strong activity-value alignments as individual participants (see table 9 for individual votes). Improve monitoring of disease and vaccines was the only top activity area voted on by tables in all three cities as aligned best with the top values. Make vaccines affordable and available to everyone, maintain high rates of vaccination of children, assure there is enough vaccine, and improve vaccine safety were important to tables in two of the three cities. Improve information offered about vaccines and improve tools for making vaccines were only prioritized by tables in one city.

Table F-5. Best Activity-Value Fits (After Table Vote)

	St. Louis (n = 11)	Columbus (n = 12)	Syracuse (n = 8)
Make vaccines affordable and available to everyone.	82%	92%	0%
Maintain high rate of vaccination of children.	64%	67%	25%
Improve monitoring of disease and vaccines.	64%	42%	100%
Improve vaccine safety.	64%	17%	100%
Assure there is enough vaccine.	55%	83%	13%
Develop new vaccines.	18%	33%	13%
Improve information offered about vaccines.	27%	8%	88%
Improve tools for making vaccines.	45%	8%	63%
Increase vaccination of adolescents.	18%	25%	13%
Increase vaccination of adults.	36%	17%	0%
Help other countries reduce disease through vaccination.	27%	8%	0%
Assure compensation for those injured by vaccines	0%	0%	0%

Appendix G. Acknowledgements

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Columbus Public Health and The Ohio State University College of Public Health
FOCUS St. Louis
F.O.C.U.S. Greater Syracuse

Appendix H. Contacts for More Information

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