



# THE CENTERS FOR DISEASE CONTROL AND PREVENTION

## MENINGOCOCCAL VACCINES FOR CHILDREN: 2011 PUBLIC & STAKEHOLDER ENGAGEMENT



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# Executive Summary

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In the summer of 2011, the Centers for Disease Control and Prevention held four public meetings across the country and engaged 277 local stakeholders and interested members of the public in a pilot project designed to get input regarding the values that could inform ACIP recommendations about whether or how to add new vaccines to the childhood immunization schedule. Participants had a general discussion about vaccines that protect children from rare but severe illnesses and a specific discussion about recently licensed and soon-to-be licensed meningococcal vaccines for infants.

The four public meetings were part of a process that also engaged national-level stakeholders in the same discussion. There was one national stakeholder meeting in advance of the public meetings (May 25, 2011) and one meeting after the four public meetings (October 5, 2011). The stakeholder meetings involved participants from a number of organizations, including the American Academy of Pediatrics, the American Academy of Family Physicians, the National Association of Pediatric Nurse Practitioners, the Heritage Foundation, the National Meningitis Association, Meningitis Angels, and Women in Government.

The public and stakeholder meetings were intended to augment the Centers for Disease Control and Prevention's (CDC) and the Advisory Committee on Immunization Practices' (ACIP) immunization decision-making processes. A primary purpose of these meetings was to gain insights into the values that people and organizations use to inform vaccine decisions. This information was summarized and provided to ACIP and the leadership of CDC's National Center for Immunization and Respiratory Diseases (NCIRD).

The values that surfaced most often during stakeholder and public meeting discussions were:

- Choice – Freedom; the ability to choose; having options with respect to immunizations; giving parents the facts and letting them decide; recommending, but not requiring; recommending, but not aggressively
- Awareness – Parents should be aware of, and have access to, infant meningococcal vaccines (or any FDA licensed vaccines)
- Access/Affordability – Cost/financial considerations should not be a barrier to vaccines
- Availability – If a vaccine is FDA licensed, parents should be able to get it; a permissive recommendation should not inhibit vaccine availability
- Safety – Few side effects; no serious risks from a vaccine
- Equity – In education, awareness, access, availability, and choice

The public and stakeholder participants used these values – informed by the discussion and deliberation with other participants, and the information provided by CDC experts during the meeting – to work through some of the vaccine program decisions facing the ACIP. The structured public meeting agenda used a number of polling questions to foster discussion, including a final question at the end of the meeting that asked participants to specifically consider the options the ACIP has with respect to new vaccines. In the final question, participants were asked, when it came to meningococcal vaccines and infants, which of the options most aligned with their values. Public meeting responses to a series

of electronic polling questions can be found in Appendix A.

Overall, about two thirds of participants indicated that a universal recommendation was most in line with their values, but for some, behind this preference was the desire for access and choice. Many recognized that adding a universal vaccine recommendation to the childhood immunization schedule would provide clear direction for physicians and parents; foster the greatest vaccine education, awareness, access, and use; address the need for education and resources; and prompt more health care providers to talk with parents about meningococcal vaccination for infants. Concerns about a universal recommendation centered on three things: 1) whether the total number of meningococcal disease cases in infants and toddlers and the number of cases that would be prevented justified a universal vaccination recommendation; 2) the number of vaccinations in the schedule; and 3) the lack of serogroup B meningococcal protection for infants and toddlers. It should be noted that this polling was not intended to generate scientifically valid data, but rather to generate discussion.

About one third of the public meeting participants favored a permissive recommendation when it came to meningococcal vaccines and infants. Some saw this choice as most in line with a value of personal choice. Many recognized that this approach would limit awareness, access, and availability of these vaccines; foster confusion and send mixed messages regarding their need; lead to inconsistencies in meningococcal vaccine use; and foster inequities in use and access of these vaccines. Some favored the addition of these vaccines to the Vaccines for Children Program (VFC) as a way to foster availability and access. Others did not favor this approach because it could result in access inequities.

Many participants expressed dissatisfaction with the available options (i.e., universal or permissive). They did not believe that meningococcal disease incidence and/or protection provided by vaccines warranted a universal recommendation; however, they also did not believe a permissive recommendation would result in physician or parent awareness of vaccines, availability of vaccines, or consistency regarding use of meningococcal vaccines for infants. Medical professionals said that doctors do not have enough time with patients to discuss all of the permissive vaccines. As such, many participants believed there should be an effort to find another recommendation option.

After reviewing the results from the public meetings, the stakeholders deliberated in their second meeting and offered these views:

**The process should, at some point, factor in cost-effectiveness and economic considerations.**

The process of public and stakeholder review of meningococcal vaccines for infants highlighted the challenges related to immunization financing and vaccine costs, including pricing. When cases of disease are relatively rare, the cost-effectiveness of vaccines can be quite low. Many public and stakeholder meeting participants said there was a need to formally factor in cost-effectiveness and economic/financial consideration. Some suggested that CDC or HHS needed a new and rigorous decision-making process that would apply standardized cost-effectiveness analyses or criteria that could be used during or after deliberations related to whether to add a vaccine to the immunization schedule.

**Immunization recommendations should ensure equity and foster access to FDA-licensed vaccines for infants and children.**

The emphasis on economic considerations during the stakeholder meetings prompted concerns that ACIP and CDC would focus too much attention on economic considerations to the detriment of equity and access. Many of the stakeholders placed a high priority on access to

new meningococcal vaccines for all children. They wanted to ensure that ACIP carefully considered in their recommendations the risk of unequal access to infant meningococcal vaccines. The stakeholders wrestled with the possibility that a permissive recommendation would lead to unintended inequities with some health care providers offering the vaccine and educating parents about meningococcal disease and other providers using their limited time with parents to talk about other vaccines or other health topics to the exclusion of information about meningococcal disease.

**It would be helpful to examine and/or expand ACIP’s options when it comes to newly licensed childhood vaccines.**

The stakeholders echoed sentiments from the public meetings and highlighted the advantages of a broader and more nuanced set of ACIP recommendation options—for example, an option that would allow for broad education and access without making meningococcal vaccination routine for all children. The stakeholder meeting participants also considered the public meetings’ call for an education strategy that recognizes the desire of many parents to have a more active role when it comes to childhood vaccines.

**Vaccine recommendations should come with provider, parent, or public education and other resources to foster awareness, adoption, and assessment of success.**

The public and stakeholder engagement made it clear that wanting options or wanting access to meningococcal vaccines for infants was not the same thing as wanting or believing there should be a recommendation that all children be vaccinated. Many participants believed that parents and providers should be aware of and have access to vaccines even if there is not a universal vaccination recommendation. Many participants recognized that adding a universal vaccination recommendation to the childhood schedule created the broadest parent and physician awareness and access.

Information about the stakeholders is included in Appendix B; full meeting summaries for the public meetings and the stakeholder meetings are found in Appendix C.

# Introduction

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In the spring of 2011, the Centers for Disease Control and Prevention’s National Center for Immunization and Respiratory Diseases (NCIRD) embarked on a project to actively involve representatives of stakeholder groups and members of the public in dialogue and deliberation related to meningococcal vaccines for infants, with one goal being to assess whether such an approach could help inform the immunization decision-making process. The objective was to discern the values that matter to people when it comes to deciding whether to add newly licensed vaccines to the childhood vaccination schedule. The project focused generally on how best to consider licensed vaccines that protect children from rare but severe illnesses and specifically on meningococcal vaccines for infants.



The CDC staff who initiated the project looked for a topic that possessed the qualities that foster successful public and stakeholder engagement: a pending decision, a decision that involves alternative courses of action, and a decision that really needs to be made (i.e., not hypothetical). In addition, the public and stakeholder engagement should serve to illuminate the choices facing policy makers, giving them a sense of the range of views that exist and the related underlying values and belief systems. The engagement process should also serve to clarify the context in which the decision will be made, including the assumptions, implications, and unintended consequences of the range of policy choices.

The project was modeled after the Public Engagement Pilot Project on Pandemic Influenza (PEPPPI), conducted in 2005 on the question of who should be vaccinated first in the early days of an influenza pandemic when vaccine supplies are still limited, and on a series of CDC projects that followed the same sequence, most recently the H1N1 public engagement project. Public engagements seek to help participants form their opinions during the meeting — in the exploration of scientific evidence, in deliberation with other members of their community, and in discussion with CDC staff. In these projects, local stakeholders and members of the public attended open, regional meetings across the United States, and a group of national-level stakeholders representing organizations most affected by the policy decisions attended two meetings — one before the public meetings and one after. The deliberations from all of the meetings were captured in a report to agency decision makers.

Independent evaluations from the prior projects indicated that this sequence of public and stakeholder engagements had been useful in CDC decision making and could continue to be, as long as the process is embedded in these principles:

- The agency desires advice on a real, unambiguous decision.
- Adequate time is given for deliberation.
- Both facts and values contribute to the choices that will be made.
- Active agency staff and sufficient resources are committed to the process.
- Both nonpartisan citizens and partisan stakeholders participate in the process.
- A critical mass of citizens and a sufficiently diverse population participate in the process.
- The process promotes mutual learning through dialogue and thoughtful deliberation.
- The participants address difficult choices.
- Recommendations receive serious consideration.
- Participants obtain candid feedback about the agency decision.

None of the previous efforts were directly connected to Advisory Committee on Immunization Practices' (ACIP) deliberation and decision making. As a result, this project served as a pilot for the possibility that CDC's model of stakeholder and public engagement could meaningfully inform the ACIP process.

## **A Project that Serves the Advisory Committee on Immunization Practices (ACIP)**

CDC selected a topic that would involve a pending recommendation from the ACIP. The project goal would be to help the ACIP members as they meet their mandate to provide advice and guidance to CDC and the CDC Director regarding:

- The control of diseases for which a vaccine is licensed in the United States
- The most appropriate use of FDA-licensed vaccines
- Population groups and/or circumstances for which a vaccine is recommended

In the near future, the ACIP will decide whether to recommend adding meningococcal vaccines for infants to the childhood vaccination schedule (often referred to as a universal recommendation) and whether to add the vaccines for infants to the Vaccines for Children Program. This decision met all of the criteria listed previously and was therefore chosen as the focus of the public engagement project.

This public and stakeholder engagement process was a supplement to ACIP's existing processes, which include working groups that gather, analyze, and prepare information; conduct in-depth reviews of vaccine-related data; and develop policy options. In the case of meningococcal vaccines, ACIP has a working group that has been involved with issues related to infant meningococcal vaccines for approximately two years.

Through its working group and its own deliberation, ACIP considers the disease epidemiology, including the morbidity and mortality associated with the disease in the general population and in specific risk groups. They also consider vaccine immune response, efficacy, effectiveness and safety, feasibility of program implementation, and economic aspects of immunization, including equity in access to the vaccine, cost-effectiveness, and responsible management of public funds.

Even without this stakeholder and public engagement process, ACIP uses information from many sources, including experts within CDC, ACIP's ex-officio members, research data, clinical trial results, information provided in the manufacturer's labeling or package inserts, recommendations of other professional liaison organizations, information from surveys or focus group findings, formal economic evaluations (e.g., cost-effectiveness, cost-benefit, cost-utility), and public comments solicited at each ACIP meeting.

As CDC staff contemplated the prospects for ACIP's recommendation on the use of meningococcal vaccines for infants, they looked at whether the particular characteristics of this set of decisions might warrant augmenting the process with additional public and stakeholder discussion. They also took into consideration many aspects of the current immunization environment, including:

- An ever-increasing number of vaccines being developed
- New combination vaccines
- Protection against relatively rare but often very serious diseases (e.g., meningococcal disease)

- Increasing cost of total vaccine expenditures
- High prices of newer vaccines
- The fact that many vaccines need two or more doses to achieve full protection
- The need to ensure access, and equitable access, to vaccines
- New constraints on public sector expenditures at all levels (local, state, federal)
- Limited, and likely decreasing, government funds
- Competing priorities at all levels
- Rising health care costs
- Very low public awareness of vaccine-preventable diseases
- Ongoing need for vaccine education and information for providers, parents, and the public
- Questions and concerns related to the total number of vaccines, the number of vaccines administered at a visit, the age at which vaccines are administered, the length of protection and vaccine safety

In addition, the agency staff reflected on a set of considerations specific to meningococcal vaccines for infants, including the following:

- Meningococcal disease is relatively rare, but can be very severe; in severe cases, illness (including limb loss) and deaths occur even with prompt treatment.
- Infant meningococcal vaccines will differ and not be interchangeable. They can prevent some but not all infections, protect for varying lengths of time, and will require several doses.
- Different recommendations from ACIP will bring very different financial and resource costs, will yield very different levels of cost-effectiveness, can foster or inhibit the availability of and access to vaccine, and can foster or inhibit disparities.

### **Adding public and stakeholder engagement to the ACIP processes**

When examining these elements of the pending decision, NCIRD staff agreed that members of the public and different stakeholders may have very different views about how to weigh the societal costs and benefits with the individual realities given the potential for severe illness and outcomes. Among the topics a wider public and stakeholder engagement effort might be expected to reveal were:

- The costs of government spending and concerns about deficits
- Expected reductions in future government funding
- The weight to give to economic evaluations
- The importance of broad access/availability of preventive measures
- Perceptions about the likelihood or possibility of being personally affected by a disease or condition
- The duty to protect others
- The role and importance of personal autonomy in vaccine decision making
- The level of investment necessary to obtain widespread protection

In contemplating whether to add public and stakeholder engagement elements to the decision making process, the NCIRD team and a small steering committee considered whether and how values — public, community, and individual — might be incorporated into the immunization recommendation decision-making process; what processes, approaches, steps, and methods should be used to uncover them; how the information about values should be used; and whether the values discussion could encompass things

like cost effectiveness, economic considerations, vaccine financing, and public resources.

The NCIRD staff decided that although public and stakeholder engagement would not supplant the existing ACIP processes and methods used to make immunization recommendations, and should not be expected to formulate the infant meningococcal vaccine immunization recommendations, it could generate insights and information that ACIP would benefit from knowing. Finally, the NCIRD staff decided to test the idea of public and stakeholder engagement as a way of seeing what might be learned about the process.

# Project Start-Up

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The first steps in the process were convening a project steering committee and a project team. The steering committee consisted of both NCIRD leaders and leaders from outside the agency who could offer advice to the project team throughout the process. The steering committee members were:

- o Janna Bardi – Program Manager, Immunization Program CHILD Profile,
- o Paul Cieslak, MD – Council of State and Territorial Epidemiologists, Child Immunizations Sub-Committee
- o Meg Fisher, MD – American Academy of Pediatrics
- o Sarah Landry, MA – Senior Advisor, HHS, National Vaccine Program Office
- o Mark Messonnier, PhD – Lead Health Economist, CDC, NCIRD Immunization Services Division
- o Kristin Pope, MA – Associate Director for Policy, CDC, NCIRD
- o Kathy Talkington – Director, Immunization Policy, Association of State and Territorial Health Officials
- o Jon Temte, MD, MS, PhD – Advisory Committee on Immunization Practices
- o Melinda Wharton, MD, MPH – Deputy Director, CDC, NCIRD

The NCIRD project team members and Mike Hughes from The Keystone Center (the lead facilitator) consulted periodically with the steering committee and gave committee members the opportunity to review agendas and other meeting materials early in the process. The NCIRD members of the project team, responsible for day-to-day project execution, were:

- o Glen Nowak – Senior Advisor/Technical Monitor
- o Michelle Basket – Acting Deputy Director, Health Communication Science Office
- o Amanda Cohn, MD – Medical Officer
- o Vicki Evans - Health Communications Specialist
- o Mattie Jones – Health Communications Specialist with Logistics Health Incorporated (LHI)
- o Alison Patti , MPH – Health Communications Specialist
- o Kondra Williams – Technical Writer-Editor

Additional members of the project team were:

- o Elizabeth Ryan , MPH – Project Director, FHI360
- o Johanna Gibbs – Public Engagement and Facilitation, The Keystone Center
- o Michael Hughes – Lead Facilitator, The Keystone Center
- o Ed Moreno – Public Engagement and Facilitation, The Keystone Center
- o Niki Koszalka – Project Support Coordinator, The Keystone Center

The project team, with the steering committee’s assistance, began by identifying public health agencies willing to host a public meeting and identifying representatives of interested stakeholder groups who would be willing to participate in the stakeholder meetings. The project team contacted 77 representatives from health care professional associations, vaccine advocacy organizations, health care advocacy groups, insurers, hospitals, consumer advocacy organizations, state and local health departments, policy think tanks, and academia. Of them, 37 agreed to attend the first stakeholder meeting. The list of participants is included in Appendix B.

# First Stakeholder Meeting

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The first stakeholder meeting, held on May 25, 2011, in Washington, DC, combined work on the vaccine decision-making questions with advice from the stakeholders on the public meeting processes (see Appendix B for list of participants). The meeting began with presentations by Glen Nowak on the ACIP processes and decision making, and Amanda Cohn on meningococcal disease, along with a panel discussion that included representatives from Meningitis Angels, the National Meningitis Association, the Penn Center for Bioethics, and BIO. Stakeholders then divided into six small groups and discussed three topics:

1. How do (and how should) values inform childhood vaccination decisions; which values should take priority over others?
2. How should cost and cost-effectiveness inform childhood vaccination decisions; what value do we place on childhood meningococcal vaccination?
3. How should the regional meetings surface answers to the same questions?

A summary of the stakeholder small-group discussions can be found in Appendix C. Highlights of the discussions include:

## Vaccines and Values

Every group affirmed that values should be considered in the immunization recommendation process and that values are an inherent part of decision making whether or not they are explicitly acknowledged. These values were repeatedly mentioned:

- Protecting the life of a child (societal value)
- Protecting the life of *my* child (individual value)
- Protecting the safety of my community (the public health value)
- Altruism
- Making well-informed and wise decisions
- Autonomy, liberty, and control
- Fairness
- Certainty/clarity/simplicity
- Protecting future generations

## Factors in ACIP (and CDC) Decision-Making

Attention to ACIP's decision-making included these ideas:

- We need to make sure that people who want more information on vaccines have access to it, including being able to view ACIP meetings online and sending comments.  
ACIP-recommended vaccines are the vaccines that doctors will discuss with their patients; doctors may be reluctant to stock and offer vaccines that are not recommended by ACIP.
- Doctors may not want to accept the risk of a vaccine side effect from a vaccine that did not get the universal recommendation from ACIP.
- Fairness comes into the discussion of vaccines that don't get an affirmative recommendation because of the ability to pay; for a non-recommended vaccine, does the doctor only offer it to individuals who can afford it?
- Parents generally follow ACIP and doctor recommendations; school *requirements* are very effective compared to flu vaccine *recommendations* for adults; many adults do not get the recommended annual flu vaccine.

- If vaccines for low-occurrence, high-impact diseases are not given a universal recommendation, there is less incentive for pharmaceutical companies to produce the vaccines; this could have implications for vaccine availability in developing countries and negative consequences for global health.
- It was generally agreed that high-occurrence, high-severity cases are the low-hanging fruit; cytomegalovirus (CMV) and respiratory syncytial virus (RSV) may be the only diseases of that type left, and so we will have to deal with future diseases which do not conform to that old profile.
- It is crucial to separate the decision about the strength of the ACIP recommendation from the decisions about vaccine mandates, which are made by local or state health officials or legislatures.
- ACIP should be aware that there are strong dualistic consequences for their recommending a universal or permissive use, and perhaps should work on creating more gray space between to make room for diseases that do not fit the old profile (e.g. low incidence, high suffering diseases or non-risk-based diseases).

### **Economic Considerations and Cost-Effectiveness**

When discussing cost, the stakeholders' statements included the following:

- As economic factors and budget deficits weigh more heavily, it's important to articulate what value we place on vaccines and how we balance protecting public and individual health with cost-containment pressures.
- Cost analyses should be done to give decision-makers another data set to consider; the cost information related to safety, effectiveness, and the overall cost of the recommendation are important.
- Economic issues should be the last consideration; if money is not a factor (no cost too high) for some prevention measures, then it should not be the determining factor in decisions related to meningococcal vaccines for infants.
- It is important to compare the prevention with the cost of treatment and care for those who contract the vaccine-preventable disease.
- It is important to understand relative costs – e.g., the cost of a vaccination program compared with the other things that we pay for as a society.
- It is important to quantify the value of illnesses prevented as a cost-saving benefit to any vaccination program.
- It is important to factor in the risks and costs of vaccine injury or potential vaccine injuries.
- It is important to remember that the health care costs are not borne equally — individuals and families bear significant costs.
- There are ways of assigning economic value to the trade-offs people make and use that economic value in decision making.
- Does reducing these values to numbers discount the human side?
- Opportunity costs matter — if large amounts of public money are spent on infant meningococcal vaccines, what other important things are we not spending money on; some in group thought this should be considered by ACIP, others did not.
- Opportunity costs are problematic when you do not know whether something good would come from the money if it was used elsewhere.
- If opportunity costs are to be considered, then questions related to them should be raised much earlier in the vaccine development process to prevent spending resources on *how* to do something only to ask *whether* to do it at the end.

- It is important to consider the costs of vaccines compared with other preventative therapies/ products and to compare the costs of one vaccine with the costs of other vaccines.
- Future vaccines depend on private sector companies' willingness to invest in research, development, and safety; as the process is currently structured, the system has to generate these incentives.
- Attempt to set a bar for defining a quality-adjusted life year (QALY) more formally — something up to \$200K; a formal threshold could make decisions clearer and more efficient.

# Four Community Meetings

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The project team selected locations and dates for the four public meetings based on state and local health departments' willingness, interest, and ability to host a meeting and to work with The Keystone Center to recruit meeting participants. Health officials in Concord, NH Seattle, WA; Chicago, IL, and Denver, CO agreed to apply their experience in conducting community meetings, and to help recruit participants using their networks of community groups, personal contacts, broadcast e-mails, social media, and traditional media. The meeting schedule was as follows:

Concord, New Hampshire – June 15, 2011  
 Seattle, Washington – July 12, 2011  
 Chicago, Illinois – July 21, 2011  
 Denver, Colorado – July 25, 2011

Leadership for the meetings came from Marcella Bobinsky and Dr. Jose Montero, New Hampshire Division of Public Health Services; Janna Bardi and Michele Roberts, Washington State Health Department; Dr. Julie Morita and Maribel Chavez-Torrez, Chicago Department of Health, and Lisa Kritz, Chicago Area Immunization Campaign; and Margaret Huffman and Joni Reynolds, Colorado Department of Public Health and Environment.

The community meetings, planned for venues that could accommodate up to 100 participants, drew this level of participation\*:

Location	# of Participants	% Female	% White	% Hispanic	% 18–50 years old	% Parents	% Parent w/child under 18
Concord	47	70%	83%	5%	43%	43%	34%
Seattle	112	75%	73%	5%	50%	49%	27%
Chicago	111	85%	39%	41%	75%	61%	34%
Denver	49	82%	81%	2%	62%	50%	26%

*\*percentages based on participants who provided demographic information*

There were many Spanish speakers who attended the Chicago meeting. Simultaneous interpretation was provided for those who needed it.

Several observers were present for each meeting; they did not vote in polling or actively participate in small group discussions. Observers included vaccine manufacturer representatives, representatives of national advocacy organizations, and members of the project team. These observers are not included in the participant numbers listed in the table above.

The meeting participants were offered a \$75 stipend. To promote participation by parents of young children, a child care stipend was added for parents of children 12 and younger for the meetings in Seattle, Chicago, and Denver.

Among participants who provided information about their employment, many came from health care

organizations (e.g., doctors, nurses, public health). In Concord, about 59% were health care workers (including public health); in Seattle, about 46%; in Chicago, about 32%; and in Denver, about 63%.

A summary of recruitment activities for each location can be found in Appendix D.

It is important to keep in mind that public meetings cannot provide statistically representative samples or groups of people. Public meetings do not involve scientifically selected or recruited samples/people, and public meetings like these are not intended to be research projects. As the information about age, ethnicity, gender and employment illustrates, the people who attended and participated in the public meetings have demographic characteristics that are different from the community as a whole. Rather, the participants were people who were interested in attending the meetings because of the topic and/or the stipend. For many, and likely most, the interest in participating in the meeting seems to have stemmed from a prior interest in immunization, including either strong support for vaccination or skepticism about the value of vaccines. Many participants indicated they had had a personal experience with vaccines or with meningococcal disease. Some parents of young children attended the meeting as did health professionals wanting to learn more or provide their views and experiences to others.

Each meeting was five to six hours in length (about 9:30 a.m. to 3 p.m.) with a highly structured agenda based on input from first the stakeholder meeting. The day began with informational presentations designed to provide everyone with enough background to be able to engage on the issue. The agenda moved from a general exploration of vaccines to the specifics of meningococcal vaccines for infants.

In an effort to give participants exposure to all the dimensions of the issue, each meeting included a presentation by an NCIRD meningococcal expert. The three NCIRD experts who served as subject-matter experts for the public meetings were:

- Nancy Messonnier, MD, Chief, Meningitis and Vaccine Preventable Diseases Branch – Concord
- Tom Clark, MD, Epidemiology Team Lead, Meningitis and Vaccine Preventable Diseases Branch – Seattle
- Amanda Cohn, MD, Medical Epidemiologist, Meningitis and Vaccine Preventable Diseases Branch – Chicago and Denver

## **Meeting Discussions**

Each public meeting included a series of facilitated large- and small-group discussions aimed at uncovering values and giving participants an opportunity to share their views and influence one another. In the whole-group sessions, electronic polling questions followed each discussion section. The polling questions (intended to reveal values and opinions and not to generate research data) allowed participants to register their views anonymously in a forced single choice. To foster helpful insights, participants were told that the day would end with polling questions with options similar to those facing ACIP (e.g., universal, permissive, and the Vaccines for Children Program decision). In considering the results of the meetings, the NCIRD staff found the discussion and the polling results helpful in providing insights into what interested and involved members of public and health care professionals thought regarding complex vaccine program questions. Polling question responses can be found in Appendix A; a full summary of each meeting can be found in Appendix C.

## Findings

When interested people were given information and engaged in extended discussion on a challenging immunization issue (i.e., the use of meningococcal vaccines to prevent meningococcal disease in infants and young children), they were able to express their values and engage in dialogue with those whose perspectives diverged from their own. They grasped the complexities and recognized that there were few, if any, simple solutions.

## Discussion Questions and Polling

When asked about **which diseases, illnesses and conditions warrant the effort to develop new vaccines**, participants frequently mentioned:

- Global impact (e.g., tuberculosis, malaria)
- Severity of the disease (e.g., MRSA, AIDS, cancer)
- (High) Frequency or prevalence (e.g., RSV, streptococcal disease)
- (High) Transmissibility or contagiousness of the disease
- Growing health issue (e.g., diabetes, asthma)
- Disease/disease burden associated with high costs

Notably, these considerations are similar to those used by ACIP in making vaccine use recommendations.

When asked to consider creating vaccines based on severity or frequency of the disease or illness, about half of the participants favored investment in vaccine development for a severe illness that affected 1 child in 100 or 1 child in 1,000 (each year).

After discussing the **characteristics of new vaccines**, the participants valued most highly:

- Safety (proven safe, good evidence of safety, few side effects)
- Effectiveness (with about half indicating a new vaccine should minimally protect 95 of 100 people vaccinated and about a fourth indicating at least 75 of 100 people vaccinated)
- Protective for a significant period of time

Participants in roughly equal numbers valued these characteristics next:

- Protects lots of people (e.g., high disease prevalence, disease is highly contagious)
- Protects against a disease that while rare is often severe

Characteristics that were not highly valued were:

- Requires few doses
- Is combined with other vaccines

In the discussion about new vaccines, these views were commonly expressed:

- Who is affected matters (e.g., children)
- How many people are affected and how contagious the illness matter
- Safety is paramount
- Vaccines need to provide protection to most who receive or the acceptance will be low
- There is a perception the childhood immunization schedule is crowded – and this should be taken into account when considering additions to the schedule

- For providers, the ability to address concerns about vaccine side effects is essential (e.g., need to have information that answers parent questions)

As for support for **immunization recommendations based on the number of children getting a severe illness in a typical year**, about 4 in 10 said 1 child out of 100 being affected made a universal vaccination recommendation a good idea (note: about 3 in 10 made that comment for vaccine development). There were differences across sites with more than half in Chicago saying 1 in 100 and most Seattle participants indicating either 1 in 1,000 or 1 in 10,000. Overall, about 1 in 4 said 1 in 100,000 or 1 in 1,000,000. Support for universal recommendations increased when disease prevalence was relatively high.

In the discussions, some of the commonly expressed views were:

- A vaccine that prevents a rare but serious disease is more important when prevention is achieved at a relatively low cost.
- The number of vaccinations and the complexity of the current immunization schedule are concerns (e.g., some feared that adding additional vaccinations might prompt more parents to delay or defer recommended vaccinations).
- Support and resources are needed when additions are made to the infant and childhood immunization schedule, and this includes:
  - \* provider resources;
  - \* parent education; and
  - \* ensuring all families/children have access.
- Parents should have (more) choice and/or options with respect to immunization recommendations.
- Parental choice is a value that should be respected.
- There should be different vaccine schedules (e.g., tiered) to accommodate different parent preferences.
- To some, adding a vaccine to the schedule was perceived as a “mandate” (i.e., “doctors want a child to receive all vaccines on the schedule” or “universal recommendations are followed by state or local actions that translate the recommendation into a requirement”)

In an effort to assess the economic/monetary value of vaccination, the participants were polled on their **willingness to pay out-of-pocket** for a vaccination that would protect a child from a rare but serious disease. In the polling, responses were more frequent at the highest options offered (e.g., more than \$150 or more than \$500). Many participants selected options in the \$50 to \$150 ranges. In the discussions, many acknowledged that looking at the issue from their child’s perspective mattered and responded with comments like these: “Of course, I would pay anything to protect my child.” Some acknowledged that it is easier to say that one would pay more than \$500, than it would be to actually pay that amount. Direct experiences with a severe disease also mattered, with participants who had direct experience with vaccine-preventable diseases indicating a willingness to pay more.

When asked **whether the cost of a vaccine should matter when it comes to recommending use for all**, participants generally expected that cost and cost-effectiveness would be a part of the ACIP/CDC decision process. In the three meetings in which this question was included in the polling, slightly fewer than half of participants indicated that cost or potential cost should be taken into account, though it should not be one of the top two or three factors. Nearly 4 in 10 indicated that cost should not matter at all, while nearly 2 in 10 said it should matter very much. The discussion about the importance of cost as a factor in vaccine decision making offered these insights:

- Many believed cost/price should not be a barrier to access to a vaccine.
- Many participants supported or advocated for “cost-benefit” and “long-term” analyses (e.g., compare the costs of using a vaccine to costs of treating those who are affected by the disease).
- For those for whom cost mattered, vaccines must be balanced against other health concerns and monetary demands within the government.
- If a vaccine is less expensive, more people will get it.
- For those for whom cost did not matter, helping to protect any children from harm means that cost should not be a factor.
- Many believed the costs associated with vaccination would most likely be less than the costs associated with the disease.

After general questions about vaccines, the discussion and polling shifted to questions specific to meningococcal disease and meningococcal vaccines for infants. Participants were most surprised about the relative lack of risk factors or other predictive conditions, the swiftness with which meningococcal disease can progress, and how much remains unknown about meningococcal disease initiation and transmission. The NCIRD subject-matter expert’s presentation and the discussion elicited these common reactions:

- Health threat seems low, but fear of threat is high
- Never heard of this until today
- This does not seem to be a major health threat
- Need better surveillance and better diagnostics
- It’s scary to see children get sick so quickly
- Images (of what disease can do) made an impact
- Education is important because:
  - Most (people/parents) probably don’t know about this disease (e.g., there aren’t many cases among infants or need increased awareness to decrease perception that ‘it can’t happen to me’)
  - Parents need to be able to make an informed decision
  - Providers are not prepared to educate parents on this

While many, perhaps most, participants had heard of meningitis, most participants had little knowledge or awareness of meningococcal vaccines, particularly with respect to vaccines for infants (as would be expected). After the presentation on meningococcal disease and vaccines, many recognized that neither the currently licensed vaccines nor those pending licensure provided protection against serogroup B, the meningococcal strain that currently causes most illness in infants and young children in the United States (i.e., many cases of meningococcal disease among infants would not be prevented by these vaccines). Many saw the lack of protection against serogroup B as a significant shortcoming (i.e., they wanted an infant vaccine to provide protection against serogroup B as well).

There was a great deal of interest in **the safety of infant meningococcal vaccines**, and participants frequently asked or raised these questions:

- What are the most common/likely vaccine reactions and how often do they occur?
- What are, or could be, the serious vaccine reactions and how often might those occur (and is it possible those could occur more often than deaths prevented by these vaccines)?
- What are the long-term effects of vaccination?

Many participants assumed that CDC had access to complete data regarding the outcomes of all or most childhood vaccinations.

When considering the **cost of meningococcal vaccines for infants** and the resources necessary for a vaccination program, some supported access/availability, making statements like “this can save lives; they should be available no matter the cost” and “every child should be able to get any licensed vaccine their parents’ want.” Others acknowledged that cost and resources mattered, making statements like “morally, costs should not matter but in reality, they do” and “all costs count; we’re in a national financial crisis.” Some believed costs were too high and expressed views such as “there is such a low level of disease, so few deaths, the cost-benefit doesn’t seem worth it for a (universal vaccination) recommendation” and “why spend a lot of money for such small results?”

Finally, at the end of the meeting day, participants had the opportunity to weigh in on **which of the options facing ACIP was most in line with their values**. The polling question offered these three options:

1. Add to the infant/childhood immunization schedule; recommend all children be vaccinated (universal recommendation)
2. No ACIP or CDC recommendation (permissive recommendation) but add to the Vaccines for Children Program
3. No ACIP or CDC recommendation (permissive recommendation) and do not add to the Vaccines for Children Program

### **Universal Recommendation**

Overall, about two thirds of participants indicated this option was most in line with their values. But for some, this preference was favored because it was seen as providing all parents the ability to learn about the vaccines and the greatest ability to have a choice to get their child vaccinated. Many recognized that adding a universal vaccination recommendation to the immunization schedule would accomplish these things:

- Provide clear direction to health care providers and parents
- Encourage greatest vaccine education, awareness, access, and use  
Trigger large(r) -scale federal government investment in infant meningococcal immunization education materials and activities
- Prompt more healthcare providers to talk with parents about meningococcal vaccination for infants

Concerns about a universal immunization recommendation for infants centered on three things: whether the total number of severe disease cases and the number of severe disease cases that would be prevented justified a universal recommendation; the high number of recommended vaccinations in the current schedule; and the lack of serogroup B protection.

### **Permissive Recommendation**

About one third of the participants favored this option. Some favored it because they saw this as most in line with a value of personal choice. Many recognized that this approach would limit awareness, access, and availability of infant meningococcal vaccines; foster confusion and send mixed messages regarding the need for and value of infant meningococcal vaccines; lead to inconsistencies in access and use of infant meningococcal vaccines; and foster inequities in use and access of infant meningococcal vaccines.

Some favored **recommending the addition of the vaccine to the Vaccines for Children Program** as a way to foster availability and access. Others did not favor this choice because it could foster access inequities (whereby low-income children would have access and those using insurance to cover the cost of the vaccine might not have access).

### **Desire for Another Recommendation Option**

Many participants expressed dissatisfaction with the available options (i.e., universal or permissive). They did not believe that the disease incidence and/or protection provided by the vaccines warranted a universal recommendation; however, they also did not believe a permissive recommendation would result in physician or parent awareness of the vaccines, availability of the vaccines, or consistency regarding use of meningococcal vaccines for infants. Many participants believed there should be an effort to find another option—e.g., one that would foster access, availability, education, and use without a recommendation that all infants be vaccinated.

### **Values**

In sum, the most frequently expressed values over the course of the project by the public meeting participants were these:

#### **Choice**

- Freedom
- Ability to choose
- Having options
- Giving parents the facts and letting them decide
- Recommending, but not requiring the vaccine
- Recommending, but not aggressively

#### **Awareness**

- Parents should be aware of, and have access to infant meningococcal vaccines (or any FDA licensed vaccines)

#### **Access/Affordability**

- Cost/financial considerations should not be a barrier to vaccines

#### **Availability**

- If vaccine is FDA licensed, parents should be able to get it
- Permissive recommendation should not inhibit vaccine availability

#### **Safety**

- Few side effects
- No serious risks from vaccine

**Equity** in education, awareness, access, availability, choice

The small group discussions made it clear that wanting options or access to meningococcal vaccines for infants was not the same as wanting or believing there should be a recommendation that all children

be vaccinated. Many participants believed that parents and providers should be aware of and have access to the vaccines even if there was not a universal vaccination recommendation. Many participants recognized that adding a universal vaccination recommendation to the childhood schedule created the broadest parent and physician awareness and access.

Among the health care providers who participated in the public meetings, these values emerged:

**Desire for clear direction**

- A permissive recommendation doesn't help providers

**Equity**

- Unless there is a reason not to, children should be treated equally
- Permissive recommendations foster inequity

**Assistance and resources**

- Providers need materials that address safety-related questions and concerns
- Providers need materials that make a strong and compelling case for vaccination

**Avoiding unintended consequences**

- Concern that new recommendations lack or divert resources
- Concern about additions to the vaccination schedule fostering vaccine delays or deferrals

Less frequently, the participants expressed that they value these as well:

- Community protection and the value of herd immunity
- Health/vaccine development leadership including the important role the U.S. plays in fostering research and development that can have benefits worldwide

# Final Stakeholder Meeting

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On October 5, 2011, the process concluded with the second stakeholder meeting at the CDC in Atlanta, Georgia. The group heard reports from the four public meetings along with a summary presentation from Glen Nowak. The stakeholders moved into small-group deliberation after a presentation from David Curry of the Penn Center for Bioethics that focused on these three questions:

1. Are values, social norms, and bioethics analysis forms of evidence?
2. How might one portray the available evidence and incorporate values?
3. How might one treat values, social norms, and bioethics in vaccine decision processes?

## Small Group Discussion

The discussions centered on three topics: the role of cost in decision making, questions of equity and access, and refining the options for ACIP recommendations.

### **Cost**

The meeting participants expected cost-effectiveness analyses to be included in the data used to make vaccine use recommendations and expected that cost-effectiveness would be a factor in deciding whether to add newly licensed vaccines to the childhood immunization schedule, particularly given the pressures on state and federal budgets. No one suggested ignoring questions related to economic considerations and cost-effectiveness. However, some participants believed in separating the roles of the ACIP and CDC, leaving ACIP to consider only the potential benefits of the vaccine and the target population, and leaving the cost-effectiveness analyses to CDC. Others expected that the ACIP and CDC should be explicit in including cost-effectiveness in their set of analyses and, in order to effectively do so, confront questions related to cost-effectiveness thresholds as well as the methodologies that would be applied to all vaccines. In this respect, the process of public and stakeholder review of the meningococcal vaccines suggested the need for a new, expanded decision-making process for CDC or HHS that would apply standardized cost-effectiveness or economic analyses to the vaccine program decisions.

Participants who had been affected by meningococcal disease offered a counterpoint to the use of economic and cost-effectiveness analyses, pointing out that they and some attendees in the public meetings believed that the possibility of preventing a serious disease and saving even one life warranted a universal recommendation, particularly when the cost of treating and caring for a person severely harmed by meningococcal disease can exceed \$1 million.

### **Equity and Access**

The emphasis on cost-effectiveness prompted concerns that ACIP and CDC would focus too much attention on economic considerations. As a result, many stakeholders in the small group discussions also focused on equity and access, placing a high priority on access to new meningococcal vaccines for all children, whether through VFC or insurance. They felt that with the current ACIP options available, the only way to achieve this broad access would be with a universal vaccination recommendation or a modification of the Affordable Care Act. A permissive recommendation with VFC would create inequities, as only children with no health insurance or limited coverage would have access to the vaccines, assuming that in this case private insurance would not cover them.

## ***Refining ACIP's Options***

The stakeholders picked up where the public meeting participants left off in discussing the specific choices facing ACIP and CDC — whether to add the meningococcal vaccines for infants to the childhood schedule (universal recommendation) or to make a permissive recommendation and, if permissive, whether to add them to the Vaccines for Children Program. The stakeholders echoed the advantages of a broader and more nuanced set of options—for example, an option that would allow for broader education and access without making meningococcal vaccination routine for all children.

With the understanding that a universal recommendation drives vaccine education, promotion, and tracking, many favored CDC action to disseminate information about meningococcal disease and about the licensed and soon-to-be licensed vaccines. They also favored efforts to get nurses, doctors, and other health care workers to discuss with their patients the risks of contracting meningococcal disease and the existence of the vaccines.

The stakeholder meeting participants also considered the public meeting participants' call for an education strategy that recognized the increasing importance of parental choice. Some in the public meetings perceived the immunization schedule as a decision made on their behalf and preferred to make their own choices regarding which vaccines their children should receive. Some believed that when CDC added a universal vaccination recommendation to the childhood schedule, it was the same as a state-level or school-district-level mandate for vaccination. In actuality, CDC does not make or have vaccination requirements for children—this is a mandate of states and school districts. Many at the meetings saw or were aware of this distinction and did not conflate the immunization schedule with mandated vaccination. Yet even among this group, there was recognition that the childhood immunization schedule is treated by many health care providers as if it were mandatory. The small-group discussion affirmed that some stakeholders were seeing these same attitudes and suggested the need to re-frame the CDC immunization schedule to make it clear that recommendations are not the same as mandates. It is important to note, however, that very high immunization coverage is needed to effectively prevent the transmission of almost all vaccine preventable diseases.

Another set of voices in favor of robust education about the vaccines came from those who have been impacted by meningococcal disease. Many stated that prior to experiencing the disease first hand they had no understanding of its severity and had not been aware that some cases could be prevented with vaccines. For them, robust education about the disease and the available vaccines were vitally important.

# Reflections on the Process

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The public meeting process attracted people with very different views and backgrounds who were able to understand and engage on a challenging and complex issue. The discussions were heartfelt and respectful. Hispanic participation and Spanish-language translation in Chicago were particularly positive.

The process drew together different organizations and created an opportunity for collaboration among federal, state and local health organizations. The four public meetings produced similar results with respect to core values and themes, giving NCIRD staff confidence that four meetings were sufficient to identify the most prevalent values and perspectives.

## Participant Evaluations

The participant evaluations highlighted these elements of the process:

- The participants were pleased that CDC staff traveled beyond Atlanta to seek community input.
- Meetings were described as “informative,” “helpful,” and “uncomfortable, worthwhile discussions.”
- Participants valued the opportunity to hear a diversity of opinions.

Many participants suggested these things:

- Expand the effort (e.g., use social media, more promotion, more communities, and additional venues).
- Hold meetings at more convenient time for parents.
- Many health professionals suggested that a survey would be more useful.
- Find ways to increase participation from a more diverse mix of parents.

Some participants expressed these views:

- A broader meeting topic (e.g., vaccines in general) would have been better.
- Although dialogue is useful, ultimately ACIP recommendations should be based on sound science.

The participants also found the public meetings valuable in these ways:

- Having an opportunity to learn about a vaccine policy question
- Having an opportunity to deliberate with one another
- Having CDC engage them in genuine dialogue on an important vaccine policy choice

In addition, the state and local health agencies deemed the work valuable in helping them work with the members of the public and with local stakeholders.

## Project Team Reflections on the Process

The team that executed the public and stakeholder engagement effort reflected on this series of meetings and on prior CDC public and stakeholder engagement that followed a similar approach (i.e., a sequence of one stakeholder meeting, followed by public meetings in different states, and finally a second stakeholder meeting).

In each project, success depended on one’s objectives. Those who were looking for a scientifically rigorous,

statistically significant statement of public opinion did not find it in this process. Those who wanted the reaction of members of the general public who had no prior stake in the vaccination question also did not find those reactions in abundance here. By recruiting through state and local health agencies and holding meetings during the work day, the team ended up convening groups of participants who had a vested interest in the topic, whether as a parent, a health care worker, or someone whose lives and loved ones had been touched by meningococcal disease or by vaccination. Therefore, it is essential to take the time at the outset of a project like this to carefully articulate the objectives and to tailor the approach to those specific objectives. These will drive recruitment strategies, time of day, location, and all other elements of the project.

This project was successful in providing these things:

- An opportunity for CDC staff and scientific experts to present information to interested members of a local community and engage in discussion with them
- An opportunity for CDC staff to share a public policy question with the public, particularly a subset of the public that is interested in participating meaningfully in policy questions, who expects public officials to operate transparently and openly, and who will not readily accept recommendations
- Unfiltered conversation among members of the community who, because of their different experiences and values, had diverse opinions about the policy question
- A process that allowed participants to consider directly the same choice policy makers will face, to see how others make that choice, and to discuss together the implications of the different choices

The following are alternative processes that NCIRD could use to improve public engagement while preserving the most important elements of this project:

#### **Less Public and More Stakeholders**

If CDC staff were to conclude that it is important to engage a wider range of stakeholders than is represented in the ACIP, as we did in this process, the agency could convene a stakeholder meeting or series of meetings to add new voices to the deliberation on an important vaccination question. In that case, stakeholders could provide input to ACIP and could even work toward a consensus of their own to be shared with ACIP. One might question whether another set of stakeholders is simply an unnecessary duplication of ACIP's work. On the other hand, it is important to consider whether a stakeholder group like the one we assembled in this case (which included those who support and those who oppose a universal recommendation) represented perspectives not included in the ACIP and whether the agency needs to hear these additional voices. However, reducing or eliminating the public portion of the engagement process sacrifices what ACIP's current processes do not already provide.

#### **Fewer Stakeholders and More Public or Parents**

If one concludes that the ACIP process is the place for input from the key stakeholders, CDC could reduce or eliminate the stakeholder portions of this process and focus greater attention on the public. Using ACIP as the forum for long-term stakeholder dialogue and augmenting the discussion with public engagement allows the agency to avoid the duplication that could come from having both ACIP and a separate stakeholder group consider the same question.

Many have observed that holding the four public meetings on a week day and recruiting through

health agencies led to participation from local stakeholders, health care providers, and interested parties rather than members of the general public. If more input from the general public is the goal, it is important to hold the meetings on the weekend and to alter the recruitment to move beyond those interested in vaccination, those who are concerned with a specific set of vaccines or disease states, or those who work in health care or public health. Public input could also be solicited in other ways, described below.

### **Citizen or Parent Panel**

CDC could use the list of participants from the four public meetings and from other public processes in order to discover parents or citizens who could be invited into a longer-term engagement focused outside of Washington, DC, or Atlanta. A panel that represents all parts of the country could be invited to continue to explore vaccine policy and bring new perspectives to the agency. The results of their deliberation could be a significant addition to the information the agency is already collecting before making an important policy decision. Keeping these local participants involved would give the agency the opportunity to create new relationships and expand its reach. Having the panel in place could also allow for relatively inexpensive and relatively quick consultation. Recruitment takes up a significant portion of time and cost on a project like this one. In addition, the panel members could be selected specifically for some attribute important to the agency for a specific policy question. For example, a panel constructed for a discussion of equity and access could include those who are of lower income and are uninsured or underinsured.

### **Large-Scale Public Meetings Targeting Specific Subsets of the Population for Public Engagement**

For specific vaccination questions, CDC could set criteria for recruitment, bringing in members of specific communities or populations. CDC could recruit parents or parents-to-be or could target income groups, age groups, or racial and ethnic groups. With carefully considered objectives for public engagement, CDC could fine-tune recruitment and create more targeted public participation while continuing to use the format for the public meetings in this project.

### **Adding Research to Engagement**

Many have pointed out that none of the meetings were representative samples. This is true; they were not intended to be. If the agency finds that engagement without public opinion research is not credible enough, a random sample survey or other statistically robust research effort can augment public or stakeholder engagement. However, public opinion research asks for opinions that are already formed. The public engagement in this case seeks to help participants form their opinions during the meeting — in the exploration of the scientific evidence, in deliberation with other members of their community, and in discussion with CDC staff. A survey cannot help the participants learn and does not allow for their opinions to develop in the way that these public meetings allowed participants to learn and form (or re-form) their opinions. If deliberation and discernment are the objectives, and if the goal is to help the members of the public gain information and only then draw policy conclusions, then public opinion research will not replace what this project was able to produce.

In the end, this public and stakeholder engagement project gives the public participants an opportunity to learn, to reflect, to deliberate, and only then to offer advice to the agency. Deliberative public engagement gives CDC input that may be useful in deciding whether to add infant meningococcal vaccination to the childhood immunization schedule. The quality of input is unlikely to be replicated in some other way. Face-to-face public meetings are valuable in illuminating the values connected to the policy question. As a result, CDC should consider continuing the public portions of the process for future ACIP recommendations and agency decision-making.

# Appendix A— Polling Results from the Four Regional Public Meetings

Note: Participants in the four public meetings were not recruited to be, nor were they, a representative sample – as such, the summary results presented below cannot be generalized to a broader community or population group.

If you were giving advice to CDC about the factors that should be given high priority when it comes to deciding how to use a new vaccine, which factor should be given the greatest weight?										
Response options	Concord		Seattle		Chicago		Denver		TOTAL	
	#	%	#	%	#	%	#	%	#	%
Protects lots of people from the disease	9	28%	32	35%	29	35%	11	37%	81	34%
Protects for a long time (e.g., at least 10 years)	7	22%	2	2%	8	10%	0	0%	17	7%
Requires few doses (e.g., 1 or 2)	0	0%	3	3%	1	1%	0	0%	4	2%
Few side effects	12	38%	22	24%	13	16%	5	17%	52	22%
Is combined with other recommended vaccines	2	6%	7	8%	5	6%	1	3%	15	6%
Protects against a disease that while rare is severe	2	6%	26	28%	27	33%	13	43%	68	29%
<b>Totals</b>	32	100%	92	100%	83	100%	30	100%	237	100%

Which type of disease do you think should be given priority when it comes to developing new vaccines?										
Response options	Concord		Seattle		Chicago		Denver		TOTAL	
	#	%	#	%	#	%	#	%	#	%
Affects lots of people but most illness is not severe	8	26%	1	1%	8	9%	0	0%	17	7%
Relatively rare, but illness is often severe	8	26%	53	59%	49	56%	17	55%	127	53%
They should be given equal priority	15	48%	36	40%	30	35%	14	45%	95	40%
<b>Totals</b>	31	100%	90	100%	87	100%	31	100%	239	100%

Thinking about vaccine development, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make an investment in a vaccine a good idea?										
Response options	Concord		Seattle		Chicago		Denver		TOTAL	
	#	%	#	%	#	%	#	%	#	%
1 child out of 100	11	33%	24	26%	38	44%	6	19%	79	33%
1 child out of 1,000	11	33%	19	21%	14	16%	6	19%	50	21%
1 child out of 10,000	5	15%	27	30%	10	12%	8	24%	50	21%
1 child out of 100,000	5	15%	12	13%	10	12%	6	19%	33	14%
1 child out of 1,000,000	1	4%	9	10%	14	16%	6	19%	30	11%
<b>Totals</b>	33	100%	91	100%	86	100%	32	100%	242	100%

# Appendix A— Polling Results from the Four Regional Public Meetings

What is the minimum acceptable level of protection that a new vaccine would need to provide?										
Response options	Concord		Seattle		Chicago		Denver		TOTAL	
	#	%	#	%	#	%	#	%	#	%
It should protect at least 25 of every 100 people vaccinated	N/A*	N/A	11	12%	7	9%	4	13%	22	9%
It should protect at least 50 of every 100 people vaccinated	8	25%	15	16%	0	0%	1	3%	24	10%
It should protect at least 65 of every 100 people vaccinated	2	6%	18	20%	5	6%	8	26%	33	14%
It should protect at least 75 of every 100 people vaccinated	6	19%	24	26%	10	12%	8	26%	48	21%
It should protect at least 90 of every 100 people vaccinated	16	50%	23	25%	59	73%	10	32%	108	46%
<b>Totals</b>	<b>32</b>	<b>100%</b>	<b>91</b>	<b>100%</b>	<b>81</b>	<b>100%</b>	<b>31</b>	<b>100%</b>	<b>235</b>	<b>100%</b>

\*This question was revised in response to evaluations from the Concord meeting.

Thinking about vaccine recommendations, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make it a good idea that all children be vaccinated?										
Response options	Concord		Seattle		Chicago		Denver		TOTAL	
	#	%	#	%	#	%	#	%	#	%
1 child out of 100	14	45%	30	33%	50	57%	7	23%	101	42%
1 child out of 1,000	6	19%	16	18%	9	10%	6	19%	37	15%
1 child out of 10,000	3	10%	29	32%	10	11%	6	19%	48	20%
1 child out of 100,000	6	19%	10	11%	8	9%	5	16%	29	12%
1 child out of 1,000,000	2	7%	6	6%	11	13%	7	23%	26	11%
<b>Totals</b>	<b>31</b>	<b>100%</b>	<b>91</b>	<b>100%</b>	<b>88</b>	<b>100%</b>	<b>31</b>	<b>100%</b>	<b>241</b>	<b>100%</b>

# Appendix A— Polling Results from the Four Regional Public Meetings

If you had to pay for a vaccine that protected your child from a rare but serious disease, what would you be willing to pay out of pocket?										
	Concord		Seattle		Chicago		Denver		TOTAL	
Response options	#	%	#	%	#	%	#	%	#	%
Zero	3	10%	8	9%	7	9%	0	0%	18	8%
Up to \$50	4	13%	18	21%	18	22%	2	7%	42	19%
\$51 to \$100	4	13%	12	14%	11	13%	8	28%	35	15%
\$101 to \$150	3	10%	15	17%	6	7%	6	21%	30	13%
More than \$150	16	54%	7	8%	4	5%	3	10%	30	13%
More than \$500	N/A*	N/A	27	31%	36	44%	10	34%	73	32%
<b>Totals</b>	30	100%	87	100%	82	100%	29	100%	228	100%

\*This question was revised in response to evaluations from the Concord meeting.

How much should the cost or potential cost of a vaccine matter when it comes to recommending its use for all infants or children?										
	Concord		Seattle		Chicago		Denver		TOTAL	
Response options	#	%	#	%	#	%	#	%	#	%
Very much -- it should be one of the top two or three factors	N/A*	N/A	14	15%	22	25%	2	7%	38	18%
Somewhat – it should be taken into account but shouldn't be one of the top two or three factors	N/A	N/A	44	49%	31	35%	16	53%	91	44%
Not at all – no price or cost is too much when it comes to preventing disease or illness	N/A	N/A	32	36%	36	40%	12	40%	80	38%
<b>Totals</b>	N/A	N/A	90	100%	89	100%	30	100%	209	100%

\*This question was revised in response to evaluations from the Concord meeting.

Which characteristic is most likely to make you want to recommend a new vaccine?										
	Concord		Seattle		Chicago		Denver		TOTAL	
Response options	#	%	#	%	#	%	#	%	#	%
It involves few doses (i.e., 1 or 2)	N/A*	N/A	0	0%	3	4%	0	0%	3	2%
It helps prevent a disease or illness that while rare, is often very severe	N/A	N/A	55	64%	42	49%	21	70%	118	59%
It is very cost effective – that is, it prevents disease at a relatively low overall cost	N/A	N/A	25	29%	20	23.5%	4	13%	49	24%
It provides protection for a long period of time	N/A	N/A	6	7%	20	23.5%	5	17%	31	15%
<b>Totals</b>	N/A	N/A	86	100%	85	100%	30	100%	201	100%

\*This question was revised in response to evaluations from the Concord meeting.

# Appendix A— Polling Results from the Four Regional Public Meetings

Which recommendation option facing the ACIP and CDC is most in line with your beliefs and values?										
Response options	Concord		Seattle		Chicago		Denver		TOTAL	
	#	%	#	%	#	%	#	%	#	%
Add to the infant/childhood immunization schedule; recommend all children be vaccinated	17	61%	47	53%	75	86%	23	79%	162	70%
No ACIP or CDC recommendation but add to the Vaccines for Children Program	5	18%	28	31%	7	8%	4	14%	44	19%
No ACIP or CDC recommendation and don't add to the Vaccines for Children Program	6	21%	14	16%	5	6%	2	7%	27	11%
<b>Totals</b>	<b>28</b>	<b>100%</b>	<b>89</b>	<b>100%</b>	<b>87</b>	<b>100%</b>	<b>29</b>	<b>100%</b>	<b>233</b>	<b>100%</b>

# Appendix B— Attendees at Stakeholder Meetings

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# Appendix B— Attendees at Stakeholder Meetings

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# Appendix B— Attendees at Stakeholder Meetings

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# Appendix B— Attendees at Stakeholder Meetings

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# Appendix B— Attendees at Stakeholder Meetings

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## Meeting 2 Participants

*Atlanta, GA, October 5, 2011*

*(cont'd)*

### **CDC (Observers)**

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# Appendix B— Attendees at Stakeholder Meetings

## Stakeholder Recruitment

The planning team made contact with the following organizations and individuals to recruit participants for the stakeholder meetings:

Organization	Name
Advisory Committee on Immunization Practices	Jon Temte
Alliance for Health Reform	Edward Howard
American Academy of Family Physicians	Kevin Burke
American Academy of Family Physicians	James Loehr
American Academy of Pediatrics	Meg Fisher
American Academy of Pediatrics	Errol Alden
American Academy of Pediatrics	Jill Stoller
American Academy of Pediatrics	Elizabeth Sobczyk
American Academy of Pediatrics – Committee on Infectious Disease	Mike Brady
American Academy of Pediatrics – Committee on Infectious Disease	Carrie Byrington
American College of Emergency Physicians	Laura Gore
American College of Emergency Physicians	Margaret Montgomery
American College of Physicians	Bob Doherty
American Enterprise Institute for Public Policy Research	Scott Gottlieb
American Medical Association	Litjen (L.J.) Tan
American Nurses Association	Katie Brewer
American Osteopathic Association	Stanley Grogg
American Public Health Association	Georges Benjamin
America's Health Insurance Plans	Barbara Lardy
Association of Asian Pacific Community Health Organizations	
Association of Childrens' Hospitals	Sue Dahl
Association of Immunization Managers	Claire Hannan
Association of State and Territorial Health Officials (ASTHO)	Kathy Talkington

# Appendix B— Attendees at Stakeholder Meetings

## Stakeholder Recruitment

The planning team made contact with the following organizations and individuals to recruit participants for the stakeholder meetings:

Autism Science Foundation	Alison Singer
babycenter.com	
BIO	Phyllis Arthur
Black Nurses Association	Millicent Gorham
Blue Cross Blue Shield Association (BCBS)	
CATO Institute	Michael Cannon
CDC, NCIRD	Melinda Wharton
CDC, NCIRD	Kristin Pope
CDC, NCIRD, Immunization Services Division	Mark Messonnier
Center for American Progress	
Center for Bioethics - Penn	David Curry
Center for Science in the Public Interest	
Children's Defense Fund	Paul Offit
Children's Hospital of Philadelphia	
CIGNA	Mark Netowski
Commonwealth Fund	
Community Health Partnership - (Santa Clara and San Mateo Counties)	Grace Melanio
Cost-effectiveness analyst	Tracy Lieu
Council of State and Territorial Epidemiologists, Child Immunizations Sub-Committee	Paul Cieslak
Dooce.com Blog	Heather Armstrong
Emory Vaccine Center	
Every Child By Two	Amy Pisani
Gates Foundation	Walter Orenstein
George Washington University, Department of Health Policy	Sarah Rosenbaum

# Appendix B— Attendees at Stakeholder Meetings

## Stakeholder Recruitment

The planning team made contact with the following organizations and individuals to recruit participants for the stakeholder meetings:

Harvard University	Meredith Rosenthal
Harvard Medical School	John Abramson
HHS, National Vaccine Program Office	Sarah Landry
healthcare economist	Frank Sloan
healthcare economist	Brian Luce
healthcare economist	Dan Polsky
Heritage Foundation	Robert Book
Howard University College of Medicine, Department of Pediatrics and Child Health	Renee Jenkins
Immunization Action Coalition (IAC)	Deborah Wexler
Immunization Action Coalition (IAC)	Diane Peterson
Immunization Alliance	
Infectious Disease Society of American (ISDA)	Leslie McGorman
Kaiser Family Foundation	Gary Claxton
Kaiser Permanente	Eric France
March of Dimes	Michael Katz
Meningitis Angels	Frankie Milley
National Academy for State Health Policy (NASHP)	
National Alliance for Hispanic Health	Medalena Castro Lewis
National Association of Community Health Centers	Molly Melbourne
National Association of County and City Health Officials	Lily Kan
National Association of Insurance Commissioners	Brian Webb
National Association of Local Boards of Health	
National Association of Nurse Practitioners	Patsy Stinchfield
National Association of Pediatric Nurse Practitioners –NAP-NAP	Catherine Carrico

# Appendix B— Attendees at Stakeholder Meetings

## Stakeholder Recruitment

The planning team made contact with the following organizations and individuals to recruit participants for the stakeholder meetings:

National Association of Rural Health Clinics	Bill Finefrock
National Coalition on Health Care	
National Consumers League	Sally Greenberg
National Council of State Legislators	
National Foundation for Infectious Diseases	Lynn Novik
National Governors' Association	
National Health Council	Myrl Wineberg
National Hispanic Medical Association	Elizabeth Gutierrez
National Medical Association	Patricia Whitley-Williams
National Meningitis Association	Lynn Bozof
National Parent-Teacher Association	Tiffany Knight
National Small Business Organization	
National Vaccine Advisory Committee	Walter Orenstein
National Vaccine Information Center	Barbara Loe Fisher
Office of Management and Budget	Tricia Schmitt
Parents of Kids with Infectious Diseases – PKIDS	Trish Parnell
Parents of Vaccine Injured Children	Vickey Debold
Partners for Prevention	Christian Johnson
Pediatric Infectious Disease Society	Penny Denehee
Pediatric Infectious Disease Society	Gary Marshall
Pharmaceutical Research and Manufacturers of America (PhRMA)	Kathleen Demore
Pharmaceutical Research and Manufacturers of America (PhRMA)	Natalie Bolea
President's Deficit Commission	
Research America	

# Appendix B— Attendees at Stakeholder Meetings

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## Stakeholder Recruitment

The planning team made contact with the following organizations and individuals to recruit participants for the stakeholder meetings:

Robert Wood Johnson Foundation	
Seattle Mama Doc	Wendy Sue Swanson
Society for Adolescent Health and Medicine	Amy Middleton
Stanford University School of Medicine	Alan Greene
Suffolk County Department of Health Sciences (Pediatric Nurse Practitioners)	Mary Beth Koslap-Petraco
Texas Children’s Hospital	Carol Baker
U.S. Chamber of Commerce	Katy Strong-Hayes
United Nations Foundation	Peg Willingham
Washington State Department of Health – Immunization and Child Profile Office	Janna Bardi
Winthrop-University Hospital	Paul Lee
Women in Government	Susan Crosby
Wyeth	Charleen Galligher

# Appendix C—Individual Meeting Summaries

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The Keystone Center’s facilitation team prepared meeting summaries for each of the two stakeholder meetings and for the four public meetings. The project team reviewed each meeting summary.

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## **Stakeholder Meeting #1 Summary**

*Washington, DC, May 25, 2011*

### **Introduction**

In the first of two meetings, 37 national-level stakeholder representatives laid the groundwork for a statement to the Centers for Disease Control and Prevention and CDC’s Advisory Committee on Immunization Practices (ACIP) about the factors that the agency should use to decide whether (and if so how) to add new vaccines to the childhood immunization schedule.

In his opening presentation, Glen Nowak, PhD, Senior Advisor, National Center for Immunization and Respiratory Diseases, framed the project as an opportunity for participants to “provide insights and views to decision makers facing a question like: How should different individual values be taken into account when formulating immunization recommendations (e.g., protecting young children from bacterial meningitis)?”

After presentations from Amanda Cohn, MD, Medical Officer, National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention; the National Meningitis Association; Meningitis Angels; BIO; and the Penn Center for Bioethics, the participants moved into six small groups to discuss three topics:

- How do (and how should) values inform childhood vaccination decisions; which values should take priority over others?
- How should cost and cost-effectiveness inform childhood vaccination decisions; what value do we place on childhood meningococcal vaccination?
- How should the regional meetings attempt to gather answers to the same questions?

### **Small Group Deliberation**

#### ***Vaccines and Values***

Every group affirmed that values must be considered in decision making process and that they are an inherent part of decision making whether or not we acknowledge them. As they discussed values, these values were mentioned repeatedly:

- Protecting the life of a child (societal value)
- Protecting the life of *my* child (individual value)
- Protecting the safety of my community (the public health value)
- Altruism — the affirmative obligation to take action if we can save a life or prevent harm, regardless of cost

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #1 Summary

*Washington, DC, May 25, 2011*

- Making well-informed and wise decisions — taking into account these things: effectiveness; risks (of taking the vaccine and of not taking the vaccine); number of people it would help; costs (to society and to individuals); and benefits (what do I get and what do we all get for the cost)
- Autonomy, liberty, control — having information and using that information to make my own choices; having the power to make my own choices, including the choices that I believe protect those I care about; freedom from coercion
- Fairness — considering whether one approach leads to a significant disparity and if that disparity is eliminated by a different approach; fairness in the distribution of individual and societal burdens and benefits
- Certainty, clarity, simplicity — we value order, clarity, and consistency; there is a sense of reaching a tipping point for parents and providers who have to face a complex and crowded vaccine schedule
- Protecting future generations — from disease, from risk/harm, from paying for benefits that accrue to this generation

### **Values Discussion**

The values discussion included these ideas:

- We demonstrate our values (what we believe in) by what we spend our money on; how much money do we spend on an illness where very few are affected?
- There is an important tension between protecting society and respecting individual choice; does a parent have a right to decide or do values of society overwhelm individual choice?
- Individual choice requires full information; if vaccine is not recommended doctors may not stock it and, therefore, may not discuss it with patients.
- Clarity, consistency, convenience for doctors and parents is essential; parents have to be prepared for the six-month visit and know what's coming; simplicity in the schedule is important.
- New recommendations should not complicate or jeopardize the whole schedule.
- We have to consider what level of risk is acceptable to our society; are we prepared to take the risk that comes with not recommending a vaccine that would save lives?
- Those making vaccination decisions have to explore and understand the trade-offs — if we make one choice over another, what are the consequences and how do these compare to the consequences of other options?
- Severity of the disease must be a consideration.
- We need a dialogue to determine the criteria to guide decision making, and to be clear and transparent as to what those criteria are.
- How do you handle the risk of meningitis? How do we quantify the risk, and do we have an acceptable or tolerable risk? Can you accept 0 deaths, 50 deaths, 100 deaths?
- Society may have overly high expectations of vaccines; they are imperfect; they may not last a lifetime; we need to more thoroughly explain vaccines to the public; people need to recognize that vaccines have mild to moderate reactions; polio vaccine had side effects, but more benefited; uncertainty is important.
- Mistrust of government and of the vaccine system and concern about vaccine side effects have to be factored in.

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #1 Summary

*Washington, DC, May 25, 2011*

- Vaccines should be available to all those who want them and in an affordable way; vaccines ought to be available, recommended, accessible.
- We could change the way the U.S. administers vaccines, making some mandatory, others recommended, and others simply available.
- Prioritize based on the impacts of contracting different vaccine-preventable diseases.
- The political process has demonstrated that vaccines are highly valued (no discussion of reducing vaccine expenditures in any health reform discussions).
- Immediacy of perceived threat/probability of contracting a particular disease will change over time.
- What is likelihood of having post-decision regret — either side effects or disease that might have been prevented?
- We are more risk averse when the stakes are high, even when the incidence is rare.
- It is not fair to subject this vaccine to higher standards of cost-effectiveness than other medical interventions (e.g., end-of-life care), other government-funded programs (e.g., entitlements like Medicare), or other federal agency (e.g., HUD) programs; perhaps they should have the higher standard as well, but it should not be a double standard.
- Values should be incorporated into the decision-making process *if* other similar decision-making processes do as well, they will be incorporated earlier, and they will be considered in the state mandate discussion stage.
- Industry should be incorporating a values discussion during their development process.
- How much debt will future generations have to take on; how will this affect other aspects of their lives?

### **Factors in ACIP (and CDC) Decision Making**

Attention to ACIP's decision making included these ideas:

- We need to make sure that people who want more information on vaccines have access to it, including being able to view ACIP meetings online and sending comments.
- ACIP-recommended vaccines are the vaccines that doctors will discuss with their patients; doctors may be reluctant to stock and offer vaccines that are not recommended by ACIP.
- Doctors may not want to accept the risk of a vaccine side effect from a vaccine that did not get the universal recommendation from ACIP.
- Fairness comes in to the discussion of vaccines that don't get an affirmative recommendation because of the ability to pay; for a non-recommended vaccine, does the doctor only offer it to individuals who can afford it?
- Parents generally follow ACIP and doctor recommendations; school *requirements* are very effective compared to flu vaccine *recommendations* for adults; many adults do not get the 'recommended' flu vaccine.
- One of the trade-offs for low-occurrence, high-impact vaccines not being recommended would be less incentive for pharmaceutical companies to use that knowledge/cross-subsidize developing- country vaccines; in other words, there may be consequences for global health.

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #1 Summary

*Washington, DC, May 25, 2011*

- It was generally agreed that high-occurrence, high-severity cases are the low-hanging fruit; cytomegalovirus (CMV) and respiratory *syncytial virus* (RSV) may be the only diseases of that type left, and so we will have to deal with future diseases which do not conform to that old profile.
- It is crucial to separate the decision about the strength of the ACIP recommendation from the decisions about vaccine mandates, which are made by local or state health officials or legislatures.
- ACIP should be aware that there are strong dualistic consequences for their recommending a universal or permissive use, and perhaps should work on creating more gray space between to make room for diseases that do not fit the old profile (e.g., low-incidence, high-suffering diseases or non-risk-based diseases)

### ***Economic Considerations and Cost-Effectiveness***

When discussing cost, the stakeholders' statements included the following:

- As economic factors and budget deficits weigh more heavily, it's important to articulate what value we place on vaccines and how we balance protecting public and individual health with cost-containment pressures.
- Cost analyses should be done to give decision makers another data set to consider; the cost information related to safety, effectiveness, and overall cost of the recommendation are important.
- Economic issues should be the last consideration; if money is not a factor (no cost too high) for some prevention measures then it should not be a determining factor in the decision about meningococcal vaccines for infants.
- It is important to compare the cost related to prevention with the cost of care for those who contract a vaccine-preventable disease.
- It is important to understand relative costs — the cost of the vaccination program compared with the other things that we pay for as a society.
- It is important to quantify the value of illnesses prevented as a cost-saving benefit to any vaccination program.
- It is important to factor in the risks and costs of vaccine injury or potential vaccine injuries.
- It is important to remember that the costs are not borne equally — individuals and families bear significant costs.
- There are ways of assigning economic value to trade-offs people make — Statistical life — measure people's values based on small changes in priorities.
- Does reducing these values to numbers discount for the "human side"?
- Opportunity costs matter — if large amounts of public money are spent on infant meningococcal vaccines, what other important things are we not spending money on; some in the group thought this should be considered by ACIP, others did not.
- Opportunity cost is problematic when you do not know whether something good would come from the money if it was used elsewhere
- If opportunity costs are to be considered, then questions related to them should be raised much earlier in the vaccine development process to prevent spending resources on *how* to do something only to ask *whether* to do it at the end.

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #1 Summary

*Washington, DC, May 25, 2011*

- Important to consider the costs of vaccines compared with other preventative therapies/products and to compare the costs of one vaccine with the costs of other vaccines.
- When numbers of incidences are so small, it makes the decisions tougher and also affects individuals' perceptions about probability of contraction; probability perception can change as proximity to or knowledge of incidences increases.
- Future vaccines depend on a private companies' willingness to invest in research, development, and safety; at present, the system has to generate these incentives.
- Attempt to set a bar for quality-adjusted life year (QALY) more formally – something up to \$200K; a formal threshold would make decisions clearer and more efficient.

### ***Suggestions for Community Input and Regional Meetings***

For the regional meetings, the participants' discussion included these suggestions:

- A wider scope of public input is necessary.
- A longer planning time and more public information are necessary before public engagement meetings.
- Diversity matters; there is probably a bias in public reporting since some people are more interested/passionate than others.
- Social media and web-based outreach are needed.
- Deliver clear, easy-to-understand information to the public.
- Involve faith-based groups and schools in community meetings.
- Presentations should reach people where they are; educational material is essential.
- Invite both vaccine-hesitant individuals and vaccine advocates.
- Conduct an initial survey about vaccines — how do you feel about vaccines in general?
- Include some demographic data.
- Scenarios: Find out whether their opinions would change depending on scenarios. Do we need a booster? What's the cost? What about giving to infants, although they're not included in clinical trials? We don't know what the safety profile of a vaccine is.
- For outreach, identify people who have an interest in the issue through experience, with meningitis, or vaccine injury. Discussion could reveal how it would affect others' willingness to take the vaccine.
- Amanda's presentation — chart on cost-effectiveness vs. different vaccine costs — allows you to connect better to the data.
- Use hypotheticals and comparable risk scenarios, like car seats, lead paint, trans fats, cancer (others disagree).
- Minimal statements; simple handouts.
- Discuss cost trade-offs and put the costs in perspective.
- What do we know from previous experience with introducing new vaccines about acceptability by parents when awareness is low, but fear is high; or when probability is low vs. severity is high (as with meningitis)?
- May be useful to group participants by stakeholder group, since there may be different educational needs.

# Appendix C—Individual Meeting Summaries

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## **Stakeholder Meeting #1 Summary**

***Washington, DC, May 25, 2011***

- Emphasize the different serotypes — make sure those facts are presented clearly.
- Should try to get people who aren't dealing with these questions every day — people who are in the middle; others disagree — want to hear about the squeaky wheels.
- Try to come up with specific questions that get at values, rather than asking people to identify their values – identify some of those things for them and ask them to weigh different specific scenarios/proposals, and then help to articulate the values trade-offs inherent in their thinking.
- Focus on the value (monetary value) of prevention.  
Cover the whole picture of risks and benefits, side-effects and protection.

## **Next Steps for the Stakeholders after the May Meeting**

Using the content of this meeting, CDC will reach out to state and local-level stakeholders and members of the public in four meetings — Concord, NH, on June 15; Seattle, WA, on July 12; Chicago, IL, on July 21; and Denver, CO, on July 25. With their work from the May 25 meeting and the results of the four regional meetings in hand, the stakeholders will meet again in the fall and conclude their deliberation. After the regional meetings, CDC's team will work with the stakeholders to create a final meeting that will give the group an opportunity to offer advice to ACIP and CDC about the factors that should guide childhood vaccination decisions.

# Appendix C—Individual Meeting Summaries

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## Childhood Vaccination Decision-Making Community Meetings

**The following objectives and context were presented at each of the four community meetings:**

This public engagement project is intended to provide information and input that can help the ACIP in its decision making regarding childhood vaccination in general and meningococcal vaccine use in children specifically. The questions/issues for stakeholders and the public are these:

- What issues (e.g., cost, disease severity, disease prevalence, vaccine supply, complexity of the market, adverse events) do stakeholders and the public see as most significant when it comes to vaccine use recommendations/adding new vaccines to the infant and childhood immunization schedule?
- What factors should be given the highest priority/most weight when it comes to recommendations regarding infant/childhood vaccines that protect against relatively rare, but often quite severe, diseases? How should ACIP/CDC consider competing values when it comes to vaccines that prevent relatively rare, but often quite harmful, diseases? How should such input be gathered and used?

# Appendix C—Individual Meeting Summaries

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## ***Concord, NH—June 15, 2011***

### **Welcome**

Dr. Jose Montero, Executive Director of the New Hampshire Department of Public Health welcomed the participants.

### **Introduction**

Glen Nowak, Ph.D., Senior Advisor, National Center for Immunization and Respiratory Diseases, introduced the topics for the day and posed these three questions for discussion:

- Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?
- If you were giving advice to scientists and others about the characteristics, qualities or features that a new vaccine should have, what would your advice be?
- What do you think are the conditions, situations, characteristics that would warrant a broad or widespread use of a new vaccine (for example, a recommendation that all children should get vaccinated)?

### **Polling Results and Plenary Discussion**

The discussion began with questions about the future of vaccine research and development. We asked the participants to identify the illnesses that should be the focus of new vaccine development and to describe the attributes that made those conditions worthy of the attention from vaccine developers. Their responses included:

- AIDS
- Diabetes
- Lyme Disease
- The Common Cold
- Heart Disease
- Strep A
- Staphylococcus
- Smoking
- Pediatric Cancers
- Malaria
- MRSA (methicillin resistant staph aureus)

The reasons for selecting these included:

- Global impact
- Severity
- Frequency and severity
- Widespread impact
- Emerging and severity
- Resistance to antibiotics, antivirals and other interventions
- High cost of the burden of disease

# Appendix C—Individual Meeting Summaries

## Concord, NH—June 15, 2011

Adding ‘who’ to ‘what’, the participants indicated that they would choose to develop vaccines for those who can’t be immunized (particularly infants), for those in the health professions, for the armed forces, and for those who cannot pay for health insurance.

### Polling Question Set 1

Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?

<b>Question:</b> Which type of disease do you think should be given priority when it comes to developing new vaccines? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Affects lots of people but most illness is not severe	8	25.8%
Relatively rare, but illness is often severe	8	25.8%
They should be given equal priority	15	48.4%
<b>Totals:</b>	<b>31</b>	<b>100%</b>

Nearly half of the participants indicated that disease severity and frequency of occurrence should be given equal priority. Remaining participants were split equally between favoring development of vaccines for the frequent/moderate disease and favoring development of vaccines for rare-but-severe disease.

<b>Question:</b> Thinking about vaccine development, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make an investment in a vaccine a good idea? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
1 child out of 100	11	33.3%
1 child out of 1,000	11	33.3%
1 child out of 10,000	5	15.2%
1 child out of 100,000	5	15.2%
1 child out of 1,000,000	1	3.0%
<b>Totals</b>	<b>33</b>	<b>100%</b>

One-third of the participants indicated that an illness that occurs in 1 child out of 100 would be an appropriate threshold for investment in a vaccine, and another third set the threshold at 1 in 1,000 children.

# Appendix C—Individual Meeting Summaries

## Concord, NH—June 15, 2011

After the first two polling questions, the participants discussed the results. Their comments included the following:

- It is important to consider the economic implications of a widespread illness, even if the symptoms are mild because so many have to stay home due to the illness.
- This is disruptive to all of society and particularly difficult for single parents.
- Attitudes toward vaccination are far more negative if a vaccine is mandated; for the moderate outcomes, even if widespread, taking the vaccine should be a choice.
- It is important to consider the implications of a low level of vaccination on long-term disease incidence.
- It is important to remember in the definition that the spectrum of illness is wide — if an overwhelming proportion experience moderate or mild illness, for some, the illness will be severe.

<b>Question:</b> If you were giving advice to scientists and others about the characteristics, qualities or features that a new vaccine should have, what would your advice be? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Protects lots of people from the disease	9	28.0%
Protects for a long time (e.g., at least 10 years)	7	21.9%
Requires few doses (e.g., 1 or 2)	0	0.0%
Few side effects	12	37.5%
Is combined with one or two other recommended vaccines	2	6.3%
Protects against a disease that, while rare, usually brings severe illness	2	6.3%
<b>Totals</b>	<b>32</b>	<b>100%</b>

Many acknowledged that for vaccination to be acceptable, new vaccines must be safe, widely effective, protective for a significant time period, and part of an efficient vaccination system, and they worried about the idea of trade-offs among these attributes. Several indicated that safety and effectiveness were paramount. When asked to select only one attribute, more than two-thirds selected safety.

<b>Question:</b> Is there a level of vaccine protection that, for you, is too low, when it comes to a new vaccine? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
It should protect at least 50 of every 100 people vaccinated	8	25.0%
It should protect at least 65 of every 100 people vaccinated	2	6.2%
It should protect at least 75 of every 100 people vaccinated	6	18.8%
It should protect at least 90 of every 100 people vaccinated	16	50.0%
<b>Totals</b>	<b>32</b>	<b>100%</b>

# Appendix C—Individual Meeting Summaries

## **Concord, NH—June 15, 2011**

Taking level of protection separately, half of the respondents stated that 90% effectiveness is necessary. One quarter would accept 50% effectiveness. The remaining participants were divided between accepting 65 and 75% effectiveness.

After the second set of two questions, the participants discussed the results. Comments included the following:

- Nothing on the list of attributes is wrong; it is difficult to choose among safety, effectiveness, and the other attributes.
- For providers, the ability to address concerns about vaccine side effects is essential; without addressing safety questions, patients will not take the vaccine.
- If the vaccine is not effective more than 80% of the time, few patients will accept it.
- People continue to believe that the flu vaccine causes the flu.
- Protecting many people is most important.
- How we talk about effectiveness can change the conversation with patients. Do we say, “The vaccine works only half of the time,” or do we say “The vaccine eliminates half of the disease”?
- It does depend on the disease; if an AIDS vaccine were 50% protective, you would have lots of people wanting that vaccine.
- There is a perception that the childhood vaccine schedule is crowded — lots of shots and combinations.
- Mercury matters; assuring patients that there is no mercury in the vaccine is necessary.
- We need higher thresholds of effectiveness and safety if a vaccine is to be mandated.
- As a society, we have forgotten the importance of herd immunity and forgotten that we get vaccinated for one another, not only for our own risk.
- The highest level of safety and effectiveness are paramount.

### **Polling Question Set 3**

What do you think are the conditions, situations, characteristics that would warrant a broad or wide-spread use of a new vaccine (for example, a recommendation that all children should get vaccinated)?

<b>Question:</b> Thinking about vaccine recommendations, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make it a good idea that all children be vaccinated? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
1 child out of 100	14	45.2%
1 child out of 1,000	6	19.3%
1 child out of 10,000	3	9.7%
1 child out of 100,000	6	19.3%
1 child out of 1,000,000	2	6.5%
<b>Totals</b>	<b>31</b>	<b>100%</b>

# Appendix C—Individual Meeting Summaries

## ***Concord, NH—June 15, 2011***

More than 45% of the participants indicated that an illness affecting 1 in 100 children would warrant vaccinating all children; just short of 20% selected 1 in 1,000 children; and just short of 20% selected 1 in 100,000 children.

<b>Question:</b> If you had to pay for a vaccine that protected your child from a rare but serious disease, what would you be willing to pay out of pocket? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Zero	3	10.0%
Up to \$50	4	13.3%
\$51 to \$100	4	13.3%
\$101 to \$150	3	10.0%
More than \$150	16	53.4%
<b>Totals</b>	<b>31</b>	<b>100%</b>

More than half of the participants said they would pay more than \$150 for a vaccine, while 10% would pay nothing.

After the third set of questions, the participants discussed the results and offered these observations:

- We have to continue to find ways to cover the cost of prevention, including the cost of vaccines.
- ACIP and CDC need new categories for vaccine recommendations between recommended and permissive; those who feel pressured and who resist the pressure to vaccinate may respond to more nuanced or tiered recommendations.
- A mom who lost her child to a rare but serious disease would have paid anything to have been able to protect her child.
- Many people cannot afford \$150 and would pay that amount only for something very important to them.
- We do not want to see the return of vaccine-preventable diseases like polio.
- Families need education and insurance coverage for these vaccines.
- To place responsibility on a parent is asking a great deal.
- Most parents are not fully aware of these recommendations and the role of CDC and ACIP.
- State legislators in legislative hearings are facing a large amount of suspicion about vaccines from the public.
- Transparency is important — we need be informed about all vaccine ingredients.
- We need a more focused effort to disseminate information about the incidence of disease and the role vaccines have played in reducing the incidence of diseases in the past, such as smallpox.
- Some parents are suspicious of vaccine manufactures, believing that companies have lobbied state legislatures to mandate the vaccine and lobbied ACIP to recommend the vaccines.
- Autism is on the rise.
- Younger generations have no idea how devastating diseases are, such as polio.
- Many younger adults who have no children also have no medical home and no place to get information.

# Appendix C—Individual Meeting Summaries

## Concord, NH—June 15, 2011

### Final Question

Question: Which recommendation option facing the ACIP and CDC is most in line with your beliefs and values? (multiple choice)		
Response options	# of Responses	%
Add to the infant/childhood immunization schedule; recommend all children be vaccinated	17	60.7%
No ACIP or CDC recommendation but add to the Vaccines for Children Program	5	17.9%
No ACIP or CDC recommendation and do not add to the Vaccines for Children Program	6	21.4%
<b>Totals</b>	<b>28</b>	<b>100%</b>

More than 60% of participants indicated that adding the vaccines to the infant/childhood immunization schedule would be the choice most consistent with their values. The remaining participants were almost equally split between favoring a permissive recommendation with the vaccines included in the Vaccines for Children Program and a permissive recommendation with no inclusion in the VFC Program.

### Small Group Discussion

To allow participants to more fully delve into the issues, participants engaged in an hour-long deliberation with a small group of participants (7 to 12 per group). This conversation was led and moderated by a small group facilitator. Groups were instructed to discuss the questions below and freely share opinions with one another; reaching consensus was not a goal of the group discussions. Themes that emerged from these small group deliberations included the following:

#### Question 1: What are people's general thoughts and assessments regarding these new vaccines?

- An education deficit exists among parents and providers regarding these issues. There is a huge need for effective health and risk communication.
- Parents need information to be able to make an informed decision about vaccination. Resources exist, such as nurse hotlines, but many parents are not aware of these resources and do not use them.
- Information needs to get to parents sooner, such as in prenatal classes.
- There is a need to build evidence-based information and provide sufficient information/data to support the recommendation.
- More information is needed regarding the efficacy and safety of these vaccines.
- The current vaccine schedule is already crowded.
- More prevention is better, through any means. One life saved is good.
- There are unrealistic expectations that vaccines will save lives 100% of the time.
- Patient time with a physician has decreased over time; there is not enough time to get all the information needed.

# Appendix C—Individual Meeting Summaries

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## ***Concord, NH—June 15, 2011***

- Where patients and parents access information has changed over time. Many receive information on the Internet or from blogs.
- How is cost considered and who should pay for the vaccine?
- These new vaccines do not protect against all strains of the disease; this may cause confusion among parents.

### **Question 2: What are your thoughts related to the health threat posed by meningococcal disease to infants and young children?**

- This disease is scary; it is scary to think children could die from a disease that is preventable.
- Education is essential in order for parents to make an informed decision. Information about the efficacy of the vaccine and the threat of the disease need to be made available and communicated to parents. Parents currently do not have enough information to understand the threat of the disease.
- There is a need for more data related to the disease pattern.
- Fear of long-term reduction of quality of life, long-term illness, and suffering.

### **Question 3: What are people's thoughts related to using these vaccines?**

These new vaccines should be included in the pediatric vaccine schedule.

- There is an opening at the nine-month checkup (currently void of vaccines).
- Anyone who wants the vaccine for their children should be able to get it, i.e., permissive recommendation; offered as part of the program but not mandatory.
- Can it be combined with Hib vaccine? Combination vaccines are more amenable to parents.

### **Question 4: In your view, what are the 2–4 things that factor most in your thinking regarding these vaccines and infants/young children?**

- Disease prevention and death due to complications from the disease
- Severity of disease (risk and threat) and frequency of occurrence
- Hearing personal stories makes the threat of disease real
- Cost of caring for disease
- Efficacy of vaccine
- Number of doses
- Cost of vaccine
- Minimal side effects of vaccine
- Difficulty in rationalizing adding another expense to society and to individuals for saving relatively few lives
- One life lost too many if the disease is preventable
- New Hampshire is a universal vaccine state
- Crowded vaccine schedule.
- Need for a national vaccine registry

# Appendix C—Individual Meeting Summaries

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## ***Concord, NH—June 15, 2011***

**Question 5: What option or options would you support most if providing input to the ACIP and CDC?**

### **Full recommendation**

- Federal funding to help states implement the programs
- Routinely recommend but not required.

### **Permissive recommendation with VFC funding**

- Permissive recommendation with choice; recommend but let parents decide whether or not to have child receive it

### **Permissive recommendation without VFC funding**

### **Other**

- Desire for a tiered approach and category of recommended vaccines

### **Other themes that emerged from small group discussions**

- There is a need for more transparency.
- Processes such as this help to inform and engage citizens in these issues; this is good.
- More research is needed related to combination vaccines, needleless systems, and vaccine efficacy.
- HPV permissive recommendation created a situation where only the wealthy can afford the shot; this type of access issue should try to be avoided in the future.
- Recommendations should come with funding support.
- Results from today's discussion and this process should factor into ACIP decision making.

## **Participant Profile**

Participants of different ages, ethnicities and parental status attended the meeting:

A majority of the participants (56.8%) were aged 51 and above, followed by participants between the ages of 31 to 50 years (38.6%). Only 4.6 percent of participants were between the ages of 18 and 30.

<b>Age range</b>	<b>Percentage</b>
18-30 years	4.6%
31-50 years	38.6%
51 and above	56.8%

While a majority of the participants were women (70.5%), only 29.5 percent were men.

<b>Sex</b>	<b>Percentage</b>
Male	29.5%
Female	70.5%

# Appendix C—Individual Meeting Summaries

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## ***Concord, NH—June 15, 2011***

While a majority of participants were white (83.3), the rest of the participants were Asian or Pacific Islander (4.8%), Hispanic or Latino (4.8%), or other (7.1%). None of the participants identified themselves as Mixed Race or Black (or African American).

<b>Race/Ethnicity</b>	<b>Percentage</b>
Asian or Pacific Islander	4.8%
Mixed Race	0.0%
Black (or African American)	0.0%
Hispanic or Latino	4.8%
White	83.3%
Other	7.1%

*Note: Not all participants chose to report their race/ethnicity.*

More than half of participants are not parents/guardians of a child 18 years old or younger (57.5%). The rest of the participants have children of varying ages: 34.1 percent have a child 18 years old or younger, 4.2 percent have a child 6 years old or younger, and 4.2 percent have a child 2 years old or younger.

<b>Are you a parent/guardian of a child 18 years old or younger?</b>	<b>Percentage</b>
Yes, my child is 2 years old or younger.	4.2%
Yes, my child is 6 years old or younger.	4.2%
Yes, my child is 18 years old or younger.	34.1%
No, I am not a parent/guardian of a child 18 years old or younger.	57.5%

*Notes: Not all participants chose to identify their parental status. Some participants selected more than one category; the first three categories are not mutually exclusive.*

# Appendix C—Individual Meeting Summaries

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## ***Concord, NH—June 15, 2011***

### **Meeting Arrangements**

- The Keystone Center worked with the New Hampshire Immunization Program to identify, evaluate, and obtain venues, secure the required audio-visual equipment, and identify meal options. In Concord, the meeting was conducted at the New Hampshire Department of Health and Human Services, Division of Public Health Services, 29 Hazen Drive, Concord, NH 03301.
- The Keystone Center worked with the local hosts to identify health department and partner staff to serve as small group facilitators and note takers at the meeting.
- Meeting attendees were recruited through a variety of activities, beginning with a mailing of recruitment materials sent by Keystone to 301 practices and approximately 1,700 providers throughout the state. The local hosts provided a list to Keystone for this mailing. Keystone and the local hosts worked cooperatively to recruit a wide range of health care professionals, parents, social services and education communities, nonprofit community leaders, and other interested parties. This was done through email networks, community calendars, and phone calls to community leaders. Keystone also worked with national stakeholder organizations to recruit through their local networks.
- Keystone worked with the local hosts, in cooperation with CDC, on a press release about the meeting. This release was sent out to media contacts throughout the state by the local hosts and resulted in two articles about the meeting.
- The Keystone Center also advertised the event through social media networks, e.g., Facebook, and through two newspaper ads, one in the *Concord Monitor* (local newspaper), and the other in the *Union Leader* (state-wide newspaper).

# Appendix C—Individual Meeting Summaries

## Seattle, WA—July 12, 2011

### Welcome

Meeting participants were welcomed by Janna Bardi, MPH, director of the Immunization and Child Profile Office, Prevention & Community Health Division, Washington State Department of Health, and Jeffrey S. Duchin, MD, chief of the Communicable Disease Epidemiology & Immunization Section, Public Health - Seattle & King County, professor in Medicine, Division of Allergy & Infectious Diseases at the University of Washington, Seattle.

### Introduction

Glen Nowak, Ph.D., Senior Advisor, National Center for Immunization and Respiratory Diseases, introduced the topics for the day and posed these three questions for discussion:

- Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?
- If you were giving advice to scientists and others about the characteristics, qualities or features that a new vaccine should have, what would your advice be?
- What do you think are the conditions, situations, characteristics that would warrant a broad or widespread use of a new vaccine (for example, a recommendation that all children should get vaccinated)?

### Polling Results and Plenary Discussion

#### Polling Question Set 1

Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?

<b>Question:</b> Which type of disease do you think should be given priority when it comes to developing new vaccines? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Affects lots of people but most illness is not severe	1	1.1%
Relatively rare, but illness is often severe	53	58.9%
They should be given equal priority	36	40%
<b>Totals</b>	<b>90</b>	<b>100%</b>

Nearly 60 % of participants selected “relatively rare, but illness is often severe” as their choice of what type of disease should be given priority for new vaccine development.

# Appendix C—Individual Meeting Summaries

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## *Seattle, WA—July 12, 2011*

<b>Question:</b> Thinking about vaccine development, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make an investment in a vaccine a good idea? (multiple choice)		
Response options	# of Responses	%
1 child out of 100	24	26.3%
1 child out of 1,000	19	20.9%
1 child out of 10,000	27	29.7%
1 child out of 100,000	12	13.0%
1 child out of 1,000,000	9	9.89%
<b>Totals</b>	<b>91</b>	<b>100%</b>

Participants overwhelmingly determined that one or more children in 10,000 would need to be protected from a severe illness to justify investment in a new vaccine - more than three fourths of all respondents. Ten percent of respondents felt a vaccine would be worth development if it protected one child in one million.

After the first two polling questions, the participants discussed the results. Their statements included these:

- Diseases are infectious and cause pain and suffering.
- For elderly people, shingles vaccines should be more widespread.
- Children should have access to immunizations, and vaccines should be fully paid for.
- Recommend vaccine research on diseases that are severe and are widespread.
- Focus on diseases that cause the most physical harm or injury to adults: cancer, stroke, heart disease.
- There should be a vaccine for autism.
- There are emerging diseases that are new to our population, such as West Nile virus.
- Vaccines are worthwhile in order to prevent the diseases that we cannot treat, such as Hepatitis C, HIV.
- Vaccines should be introduced once there is a baseline study.
- Participant is bothered by wording of questions: lots of people, and severe, favoring a percentage.

# Appendix C—Individual Meeting Summaries

## Seattle, WA—July 12, 2011

### Polling Question Set 2

If you were giving advice to CDC about the factors that should be given high priority when it comes to deciding how to use a new vaccine, what would your advice be?

<b>Question:</b> If you were giving advice to scientists and others about the characteristics, qualities or features that a new vaccine should have, what would your advice be? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Protects many	32	34.8%
Protects for a long time (e.g., at least 10 years)	2	2.2%
Requires few doses (e.g., 1 or 2)	3	3.3%
Few side effects	22	23.9%
Is combined with one or two other recommended vaccines	7	7.6%
Protects against a disease that while rare, usually brings severe illness	26	28.2%
<b>Totals</b>	<b>92</b>	<b>100%</b>

More than a third of the respondents chose ‘protecting lots of people from the disease. For another 28%, vaccinating people to prevent a disease that is rare but brings a severe illness was most important. Approximately a quarter of the participants chose few side effects.

<b>Question:</b> What is the minimum acceptable level of protection that a new vaccine would need to provide?		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
It should protect at least 25 of every 100 people vaccinated	11	12.0%
It should protect at least 50 of every 100 people vaccinated	15	16.5%
It should protect at least 65 of every 100 people vaccinated	18	19.8%
It should protect at least 75 of every 100 people vaccinated	24	26.4%
It should protect at least 90 of every 100 people vaccinated	23	25.3%
<b>Totals</b>	<b>91</b>	<b>100%</b>

Respondents increasingly favored vaccines that provided greater protection, with support gradually increasing with each increment, up to 75%. Almost the same number of respondents favored a minimum level of 75 out of 100 and 90 out of 100.

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

After these polling questions, the participants discussed the results, producing the following insights:

- At CDC and ACIP meetings, vaccine safety is not a priority. People who are knowledgeable about statistics need to relay the numbers of adverse reactions of vaccines to the ACIP/CDC.
- How likely are you to die from an illness? This answer will affect my acceptable level of effectiveness of a vaccine.
- Health care provider: In Washington state, effectiveness generally follows the 80/20 rule — 80% effectiveness of a vaccine is the informal threshold.
- Mother of four children concerned about vaccine safety.
- Physician who contracted polio before there was a vaccine wants to see good science behind health conditions. More efforts are needed to educate the public on the importance of vaccination so they can make informed decisions.
- Effectiveness and complication rate cannot be separated.
- How easily does the disease spread?
- Education is crucial for adults and teenagers.
- Parents are not educated about the risks or benefits of a vaccine. Parents get advice from friends, relatives. Education is the basis of success of vaccination.

### **Polling Question Set 3**

<b>Question:</b> Thinking about vaccine recommendations, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make it a good idea that all children be vaccinated? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
1 child out of 100	30	33.0%
1 child out of 1,000	16	17.6%
1 child out of 10,000	29	31.9%
1 child out of 100,000	10	10.9%
1 child out of 1,000,000	6	6.6%
<b>Totals</b>	<b>91</b>	<b>100%</b>

More than 80% of respondents said it would be a good idea to develop vaccines to protect up to 1 child in 10,000 from a severe illness from a disease. Nearly 7% said they would support a vaccine if it protected 1 child in a million.

# Appendix C—Individual Meeting Summaries

## Seattle, WA—July 12, 2011

<b>Question:</b> If you had to pay for a vaccine that protected your child from a rare but serious disease, what would you be willing to pay out of pocket? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Zero	8	9.2%
Up to \$50	18	20.7%
\$51 to \$100	12	13.8%
\$101 to \$150	15	17.2%
More than \$150	7	8.1%
More than \$500	27	31.0%
<b>Totals</b>	<b>87</b>	<b>100%</b>

Respondents selected the low to mid-range of choices for how much they would be willing to pay for a vaccine to protect a rare but serious disease. More than half selected the range between up to \$50 to \$150.

<b>Question:</b> Which characteristic is most likely to make you want to recommend a new vaccine? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
It involves few doses (i.e., 1 or 2)	0	0%
It helps prevent a disease or illness that, while rare, is often very severe	55	63.9%
It is very cost effective — that is, it prevents disease at a relatively low overall cost	25	29.1%
It provides protection for a long period of time	6	7.0%
<b>Totals</b>	<b>86</b>	<b>100%</b>

A vaccine that prevents a rare but severe disease was more important than whether the prevention is achieved at a relatively low cost. How long the vaccine protects a person received little support and no respondent selected that a small number of doses was important.

# Appendix C—Individual Meeting Summaries

## Seattle, WA—July 12, 2011

<b>Question:</b> How much should the cost or potential cost of a vaccine matter when it comes to recommending its use for all infants or children? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Very much — it should be one of the top two or three factors used in determining whether a vaccine should be recommended for all infants or children	14	15.5%
Somewhat — it should be taken into account but shouldn't be one of the top two or three factors considered	44	48.9%
Not at all — no price or cost is too much when it comes to preventing disease or illness	32	35.6%
<b>Totals</b>	<b>90</b>	<b>100%</b>

Half of the respondents said the cost or potential cost of a vaccine should matter when it comes to recommending its use for all infants or children. Another third of the respondents said it should not be a factor at all when it comes to preventing illness. Only 15% said it should matter a lot.

### Final Question

<b>Question:</b> Which recommendation option facing the ACIP and CDC is most in line with your beliefs and values? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Add to the infant/childhood immunization schedule; recommend all children be vaccinated	47	52.8%
No ACIP or CDC recommendation but add to the Vaccines for Children Program	28	31.5%
No ACIP or CDC recommendation and don't add to the Vaccines for Children Program	14	15.7%
<b>Totals</b>	<b>89</b>	<b>100%</b>

A majority of the respondents said that adding a recommended meningococcal vaccine to the infant/childhood immunization schedule was most consistent with their beliefs and values. Almost one-third of the respondents said they would not favor a recommendation, but that the vaccine should be available to participants in the Vaccines for Children Program. Fifteen percent said their values would not support a recommendation or adding the vaccine to the VFC program.

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

A majority of the respondents said that adding a recommended meningococcal vaccine to the infant/childhood immunization schedule was most consistent with their beliefs and values. Almost one-third of the respondents said they would not favor a recommendation, but that the vaccine should be available to participants in the Vaccines for Children Program. Fifteen percent said their values would not support a recommendation or adding the vaccine to the VFC program.

Discussion following the polling question generated the following comments:

- Losing a child to meningitis causes suffering
- Every child should be vaccinated against the disease; economic factors should not factor into the final decision
- Parents should be educated on the disease to make better decisions
- Vaccinate all children.
- Once the CDC makes a recommendation, it becomes a mandate and any parent that does not comply with mandate is deemed irresponsible and a threat to society
- There is a need to respect a parent's right to individual choice and allow different vaccine schedules for different families.
- More culturally appropriate information to educate individuals from all different backgrounds is needed
- Concern that vaccinations may be unsafe or not useful
- Children have died from vaccination itself, which has been ignored by the media
- Important to give information to teenagers
- Need to know how to give information to teenage parents
- All side effects are recorded in an open database where people can get information; when your arm is sore after a vaccination that is the immune system working
- Though vaccines are safe, there are many individuals who cannot accept the vaccine due to health reasons
- Parents make a decision based on a perceived vaccine risk, not on actual vaccine safety, risks and benefits
- The overall risks and benefits are important to focus on; the disease affects very few people; if the vaccine is recommended, there would be one in 50,000 who get the disease, but two who have a severe adverse reaction — aren't you making the problem worse?
- Would not want to give his kids a vaccine that has not been adequately tested, and whose mortality rate may be more than of the disease.
- Important to explore vaccine immunity versus natural immunity. When meningitis is found naturally in our body, our body reacts to this; when vaccinated, we create artificial immunity that is not life-long but requires boosters and fades with age. For future generations, how will we pass natural immunity on to our children if we use vaccines, and how will this affect one generation to the next?
- If CDC does not recommend the vaccination, fears that parents will not have the choice to decide whether or not to vaccinate their children. We have the freedom to choose; if it's not on the schedule, you would not know about the vaccine.

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

### **Small Group Discussion**

To allow participants to more fully delve into the issues, participants engaged in an hour-long deliberation with a small group of participants (7 to 12 per group). This conversation was led and moderated by a small group facilitator. Groups were instructed to discuss the questions below and freely share opinions with one another; reaching consensus was not a goal of the group discussions. Themes which emerged from these small group deliberations included the following:

#### **Question 1: What are your thoughts related to the health threat posed by meningococcal disease to infants and young children?**

- Education — the need to understand the risk factors, to be able to make better decisions. Help people make educated decisions.
- People need to know enough to be able to give informed consent.
- Truthful and accurate information is needed.
- Choice — important to opt out if you do not want the vaccine, without consequences for parents who do so.
- Vaccine laws viewed as “mandates” — no longer a free country; should not be mandated.
- If it is not recommended, people would not even be able to decide.
- Access to vaccines should be a right.
- Providers do not always give patients a choice — practices differ.
- Prevention is beneficial and would prevent devastation for a family.
- People have a social responsibility to vaccinate.
- One participant gave teenager the meningitis vaccine not for his protection, but for the greater good.
- My child has the right to be free of threats from unvaccinated children.
- Providers should ask their clients: “What are you afraid of?” and then help the clients make a decision.
- Concern about how meningitis spreads — everyone deserves immunity.
- It is so rare, you might think, “It won’t happen to my kid.”
- A hideous disease. Children die of many things, all ways are bad. We lose more infants to car accidents than to meningitis.
- If we can prevent this devastation, we should.
- It takes too long to identify the disease once an individual starts to get sick.
- Doctors will screen infants with symptoms for meningococcal disease.
- There should be a quicker diagnosis - time versus severity.
- Need better surveillance — easier test to confirm.
- It is so deadly, you have to drop everything else to treat people who came in contact, even if they have been vaccinated, because of the different strains.
- There is a difference between meningococcal disease (more severe illness, disease is in an individual’s blood stream) and meningitis. In my career as a doctor, only 8 children have been infected with meningococcal disease.
- Would there be an outbreak if large numbers of immigrants come from a country where meningitis is prevalent?
- Confusion over shift among strains of meningitis.

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

- Since the number of infected each year is so low, do not see the health threat as very severe — believe there is too much of a bias/sales pitch for the vaccine.
- Does not seem to be a huge health threat.
- The health threat seems low, but the fear of threat is high.
- No one speaks for those who are disabled or die from vaccine-preventable disease.
- I lost a child to meningitis; I think the health threat is high.
- Concerned that the vaccine is not as effective as desired — protects 75 out of 250 — many cases are not preventable by vaccine.
- Overall health threat is less than everyday things.
- Vaccine injury risk — significant costs to recovery and can be a lifelong struggle.
- I don't understand why we're discussing this other than pharmaceutical companies want to sell it.

### **Question 2: What are people's general thoughts and assessments regarding these new vaccines?**

- Proportionally fund the big diseases, but don't ignore the rare ones.
- Weighing the risks versus severity.
- Is it worth it with one person being killed? Severity of meningitis is more important.
- Surprised by the small numbers of affected people.
- Correlations should be made specific to area populations.
- This government money could be spent on other programs that would benefit a larger number of people, for example, WIC, breast exams, etc.
- No predictors for this disease.
- They're not making up these diseases; we're not in fear of nothing.
- Educate teenagers (higher-risk) about the risks and sharing things.
- Unvaccinated children can be vectors to other children.
- Consider exposing to already-exposed children to get the disease naturally.
- Ethics — vaccination is mandated to get a public education.
- Parents don't always see the vaccine exemption forms.
- CDC is a marketing tool for the drug companies.
- Why not have drug companies sell it without a recommendation?
- Washington State has investments in drug companies.
- There will be large profits made by a recommendation; question motivations of doctors, companies, and media.
- Lots of money is being spent for small return, focus on primary care and prevention.
- More testing — 7,000 people are not enough.
- Pros should outweigh the cons.
- Don't just add a vaccine; replace ones that are not as effective.
- Concerned that it does not cover all serotypes,
- Trust in medical community, educate yourself.
- If multiple shots were a problem, you would see something.
- So many shots at one time and such little babies.

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

- The schedule is full enough; give us data on all vaccines.
- Where does this vaccine stuff stop?
- Concern over artificial immunity that may be/is created through vaccination.
- Not enough focus on safety; I'm concerned about vaccine safety.
- Haven't seen research that there are lots of side-effects.
- My child had an adverse reaction to vaccine, and I have hesitancy with vaccine schedule.
- Consider the cost of settlements (vaccine injuries). Test for vaccine injury susceptibility.
- They should study people who don't get any vaccines — unvaccinated study.
- Should consider alternate schedules in combinations for fewer injections.
- There is a lot we do not understand with these vaccines and serotypes.
- Dedicate funds for treatment or diagnosis.
- Put money into doctors' education and diagnosis.

### **Question 3: What should or does CDC need to take into account when it comes to making recommendations related to these vaccines?**

- If there are combinations, what are the implications?
- The number of shots; there should be more combinations.
- Can there be both single vaccine and combinations?
- Opposite view: combination shots are riskier, a recipe for more injury.
- Seizure rate will increase with more shots.
- More testing — 7,000 subjects are not enough.
- Produce evidence of honest research.
- Scientists should present data in a way the public can understand.
- Science is suppressed on vaccines; information is coming from drug companies.
- Independent labs should validate results.
- Assurance that the government is not suppressing science for political goals.
- Underserved populations, poor people should have access to care.
- Equal access for both rich and poor.
- Concern about cost if not recommended.
- Cost is important, but OK to pay more if it is known to be safe
- Have insurance, but without it I could not afford vaccine.
- Should consider the costs of taking care of injured survivors.
- Not just the severity, but how fast this (meningitis) happens.
- Better ability to diagnose meningitis is needed.
- Number of people affected, severity, costs, and number of doses.
- Why exclude this vaccine when children are exposed?
- Disease and deaths prevented is number 1; number of doses is low consideration.
- How many interventions are needed to prevent one case?
- Need for more information to the public, right now it is not good.
- CDC needs to understand the public's perception of disease and medical errors.

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

- CDC is not doing a good enough job of showing they are doing a good job for the public.
- Present parents with detailed information.
- Is there enough information to provide informed consent?
- People have a right to know if a child away at university has been vaccinated.
- Provide information on the science of how the diseases work.
- Information is critical, statistics can prove anything.
- Parents should have options — permissive.
- ACIP recommendation opens conversations between parents and providers.
- Historical issues — Native Americans infected with smallpox; who’s giving me information I can trust?
- New Washington law is unconstitutional (opinion).
- Trade-off between infection and autoimmune disorder.

### **Question 4: Does, or should, the price of a vaccine or the overall cost of an immunization recommendation matter, when it comes to decisions about how to use new vaccines?**

- You can’t put a price on life.
- There is no cost factor in getting to safety.
- It should be available no matter what the cost.
- Prevention (versus treatment) saves money.
- If limited money, I prefer prevention.
- Every child should get any vaccine their parents want.
- Costs us \$950 a month for our son’s care.
- The treatment for the illness costs a lot of money; we didn’t hear a lot about lifetime costs.
- Costs are too complex.
- Why spend a lot of money for such small results?
- There is such a low level of disease, so few deaths; the cost/benefit does not seem worth it.
- Spend proportionately: severity versus incidence.
- Cost should not be a consideration, but it already is.
- It should not be too expensive.
- Of course, it matters.
- Costs matter because states bear the burden.
- Cost will decrease over time with production.
- If you’re poor, it’s a “Sophie’s Choice” situation (only bad choices).
- Would be worried that some people who could not afford it, and impact on society.
- If it’s recommended, it should be available to all.
- Pharmaceuticals are a \$25 billion and growing business. This (meeting/process) is a path for them to market their products.
- Trust issue — FDA, CDC, Pharma do not support alternative health options.
- Public health should be conducted by nonprofit organizations.
- Our national priorities are mixed up — favoring bombers over immunizing children.

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

- Depends on if it's covered by insurance.
- It should be considered — it must be paid for by public funds.
- OK with taxes going to the vaccine program; for helping the most kids.
- With the low incidence under 2 years old, how about FDA approval but only recommend for risk groups?

### **Question 5: What option or options would you support most if providing input to the ACIP and CDC? Recommended with (below options)**

- Education — get the most amount of education out there; role of CDC; rationale for adding to the schedule
- Weigh the risks and benefits; pros and cons.
- More safety testing; more data collection
- Available to all, including VFC
- Covered by insurance
- Parental choice; flexible schedule
- If it covered the B serotype
- Only for at risk groups
- Not a mandate

### **Permissive with (below options)**

- Included in VFC
- Not like other childhood vaccinations
- Not convinced that it should be routine
- False assurances; parents are not being educated
- This disease is not an epidemic, let parents decide whether to vaccinate

### **Unclassified**

- Group poll: evenly split between recommended and permissive (w/VFC), with personal opt-out.
- There should be another level of recommendation — something in between recommended and permissive.
- We don't have enough information to decide today.
- Base recommendations on age groups.
- Help patients navigate the choices.
- There should be a better diagnostic test.
- Parents need more education about the choices.
- Doctors don't always know which vaccines are required.

### **Question 6: Are efforts like this community meeting a good idea when it comes to developing immunization recommendations?**

- Good to hear about CDC and their work
- To hear other peoples' views; fascinating to hear others

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

- Meeting assumed that vaccines are safe, I disagree with that; not inclusive of those who are skeptical about vaccination
- More data on clinical trials
- Too much slide show, not enough talking
- Should be presented in simpler form
- Want more information on cost and adverse side effects
- Good educational experience
- Very helpful, honest conversation
- 20 minutes of open comment was great
- Random focus groups should be asked this
- Feel like I am being heard
- Not diverse enough (Seattle)
- Short meetings with several groups
- Evening meetings
- Provide child care
- Transportation
- Cultural differences
- Involvement
- Use sports teams' mailing lists
- Process would be better if people were convinced input will really be used by CDC
- More young people
- Teen mothers
- No, not a good idea
- Proactive patients needed to change the culture to allow patients to ask questions
- Physicians do not have enough time with patients
- CDC website is WAY too complicated, "too over my head" – needs to be put into terms that all understand

### **Other themes that emerged from small group discussions**

- There is a need for more transparency.
- Processes such as this help to inform and engage citizens in these issues; this is good.
- More research is needed related to combination vaccines, needleless systems, and vaccine efficacy.
- HPV permissive recommendation created a situation where only the wealthy can afford the shot; this type of access issue should try to be avoided in the future.
- Recommendations should come with funding support.
- Results from today's discussion and this process should factor into ACIP decision making

# Appendix C—Individual Meeting Summaries

## Seattle, WA—July 12, 2011

### Participant Profile

Half of the participants (50%) were 51 years old and above. Slightly less than half (38.4%) were between the ages of 31 to 50. Only 11.6 percent were between the ages 18 and 30.

Age range	Percentage
18-30 years	11.6%
31-50 years	38.4%
51 and above	50.0%

The majority of participants were women (75.2%). Only 24.8 percent were men.

Sex	Percentage
Male	24.8%
Female	75.2%

A majority of participants (72.8%) identified White as their race or ethnicity. The remaining participants identified themselves as Other (8.7%), Asian or Pacific Islander (5.3%), Black (or African American) (5.3%), Hispanic or Latino (5.3%), and Mixed Race (2.6%).

Race/Ethnicity	Percentage
Asian or Pacific Islander	5.3%
Mixed Race	2.6%
Black (or African American)	5.3%
Hispanic or Latino	5.3%
White	72.8%
Other	8.7%

*Note: Some participants identified themselves as more than one race or ethnicity.*

Slightly more than half of participants reported that they are not parents or guardians of a child 18 years old or younger. On the other hand, about one-fourth (26.73%) stated that they are parents or guardians of a child 18 years old or younger. Participants also reported having younger children: 12.87 percent have a child 6 years old or younger and 8.91 percent have a child 2 years old or younger.

Are you a parent/guardian of a child 18 years old or younger?	Percentage
Yes, my child is 2 years old or younger.	8.7%
Yes, my child is 6 years old or younger.	12.9%
Yes, my child is 18 years old or younger.	26.7%
No, I am not a parent/guardian of a child 18 years old or younger.	51.7%

*Note: Not all participants chose to report their parental status. A few participants selected more than one category.*

# Appendix C—Individual Meeting Summaries

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## ***Seattle, WA—July 12, 2011***

### **Meeting Arrangements**

- The Keystone Center worked with local hosts to identify, evaluate, and obtain venues; secure the required audio-visual equipment; and identify meal options. The meeting was conducted in the Shoreline Community Center; the Washington State Department of Health (WSDOH) arranged for an affiliated agency to provide meals for the participants.
- The Keystone Center was responsible for identifying and recruiting facilitators.
- Attendees were recruited through a variety of activities, beginning with health care professionals with whom the WSDOH regularly communicates and a press release. Keystone followed leads provided by the WSDOH and developed other leads to a number of social service organizations, community networks, and other organizations that would be interested in the topic. Keystone identified a score of websites and social media avenues through which to disseminate the information.

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

### **Welcome**

The meeting participants were welcomed by Julie Morita, M.D., Deputy Commissioner, Public Health and Safety, Chicago Department of Public Health.

### **Introduction**

Glen Nowak, Ph.D., Senior Advisor, National Center for Immunization and Respiratory Diseases introduced the topics for the day and posed these three questions for discussion:

- Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?
- If you were giving advice to scientists and others about the characteristics, qualities or features that a new vaccine should have, what would your advice be?
- What do you think are the conditions, situations, characteristics that would warrant a broad or widespread use of a new vaccine (for example, a recommendation that all children should get vaccinated)?

### **Polling Results and Plenary Discussion**

The discussion began with questions about the future of vaccine research and development. The participants were asked to identify the illnesses that should be the focus of new vaccine development and to describe the attributes that made those conditions worthy of the attention from vaccine developers.

The responses included:

- MRSA - It's a superbug, antibiotic resistant, more prevalent now, a pandemic in the making
- Streptococcal disease - There are 60 strains of the disease, a frequent illness, lots of children coming into doctors' offices, it's contagious to family members.
- Tuberculosis - It's a disease that affected a great number of people; still a very serious disease that affects a smaller number of people.
- Asthma - there should be a vaccine for that.
- What does CDC think? How do they make these decisions? On the basis of what is most prevalent or is it politically driven?
- Autism- It's affecting a great number of people.
- What are the diseases and illnesses that are expensive, for both individuals and the government? Think about the diseases that are very expensive to treat.

# Appendix C—Individual Meeting Summaries

## Chicago, IL—July 21, 2011

### Polling Question Set 1

Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?

<b>Question:</b> Which type of disease do you think should be given priority when it comes to developing new vaccines? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Affects lots of people but most illness is not severe	8	9.2%
Relatively rare, but illness is often severe	49	56.3%
They should be given equal priority	30	34.5%
<b>Totals:</b>	<b>87</b>	<b>100%</b>

More than half of the respondents selected the relatively rare but often severe disease as the priority for vaccine development. Another third of the respondents said severity and frequency should be given equal consideration.

<b>Question:</b> Thinking about vaccine development, for you, how many infants and children would need to get a severe illness - that is, an illness that results in hospitalization, death and/or a life-long disability - from the disease in a typical year in the U.S. to make an investment in a vaccine a good idea? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
1 child out of 100	38	44.2%
1 child out of 1,000	14	16.3%
1 child out of 10,000	10	11.6%
1 child out of 100,000	10	11.6%
1 child out of 1,000,000	14	16.3%
<b>Totals</b>	<b>86</b>	<b>100%</b>

The overall trend of the responses was that serious diseases that affect more children should have more investment for vaccine development. The responses declined as the disease frequency declined.

# Appendix C—Individual Meeting Summaries

## **Chicago, IL—July 21, 2011**

After the first set of polling questions, the participants discussed the results. Their statements included the following:

- Diseases are infectious and cause pain and suffering.
- It matters who and how many get sick, along with the risk and ease of getting the disease.
- Education is important — so people understand the risks, pros and cons.
- People trust their providers; providers need information.
- There should be some emphasis on those in the childbearing years — a large population that takes care of everyone; the women in this age group are the core of families that take care of children and elderly.
- If the FDA approves a vaccine, it would be useful for some group. Let's put it in the hands of patients and doctors. Why would the CDC not be able to approve these? Should approve everything that is safe and effective. Discretion should be for doctors and patients.
- CDC should monitor the vaccines that are expiring. Do not waste anything.
- There should be more focus on previous medical history; talk to doctors about previous medical issues and family history, to identify side effects.
- Make sure the benefits outweigh the risk and focus on individual health risk.

### **Polling Question Set 2**

If you were giving advice to CDC about the factors that should be given high priority when it comes to deciding how to use a new vaccine, what would your advice be?

<b>Question:</b> If you were giving advice to CDC about the factors that should be given high priority when it comes to deciding how to use a new vaccine, which factor should be given the greatest weight? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Protects lots of people from the disease	29	35.0%
Protects for a long time (e.g., at least 10 years)	8	9.6%
Requires few doses (e.g., 1 or 2)	1	1.2%
Few side effects	13	15.7%
Is combined with one or two other recommended vaccines	5	6.0%
Protects against a disease that while rare usually brings severe illness	27	32.5%
<b>Totals</b>	<b>83</b>	<b>100%</b>

Responses were closely balanced between protecting a lot of people from a disease, and severe diseases that are rare, with about one-third favoring each. About 15% responded that few side effects would be the most important factor.

# Appendix C—Individual Meeting Summaries

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## **Chicago, IL—July 21, 2011**

<b>Question:</b> What is the minimum acceptable level of protection that a new vaccine would need to provide?		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
It should protect at least 25 of every 100 people vaccinated	7	8.6%
It should protect at least 50 of every 100 people vaccinated	0	0.0%
It should protect at least 65 of every 100 people vaccinated	5	6.2%
It should protect at least 75 of every 100 people vaccinated	10	12.4%
It should protect at least 90 of every 100 people vaccinated	59	72.8%
<b>Totals</b>	<b>81</b>	<b>100%</b>

Three-fourths of the respondents said that a new vaccine would have to cover at least 90% of those vaccinated from a disease for it to be used. Responses dropped sharply for anything less effective.

After the second set of polling questions, the participants discussed the results. Their statements included the following:

- If you are going to use the vaccine for everyone, it should be safe.
- You should consider the severity and contagiousness of the disease before deciding to use the vaccine.
- Consider the long term results/outcomes from the disease.
- Consider the long term effects of the vaccination.
- Measure the quality of life — how much more life you have. If it protects you for your life, you should get it.
- If FDA approves it is safe and effective, you should get it out to as many people as far as possible, as fast as possible.
- Cost of the vaccine — if it is less expensive, more people will get it.

### **Polling Question Set 3**

What do you think are the conditions, situations, characteristics that would warrant a broad or widespread use of a new vaccine (for example, a recommendation that all children should get vaccinated)?

# Appendix C—Individual Meeting Summaries

## Chicago, IL—July 21, 2011

<b>Question:</b> Thinking about vaccine recommendations, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make it a good idea that all children be vaccinated? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
1 child out of 100	50	56.8%
1 child out of 1,000	9	10.2%
1 child out of 10,000	10	11.4%
1 child out of 100,000	8	9.1%
1 child out of 1,000,000	11	12.5%
<b>Totals</b>	<b>88</b>	<b>100%</b>

More than half of the respondents said that all children should be vaccinated to protect them from a common, severe disease. The remaining 43% of the responses allocated to the other ratios were within three points of each other.

<b>Question:</b> If you had to pay for a vaccine that protected your child from a rare but serious disease, what would you be willing to pay out of pocket? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Zero	7	8.5%
Up to \$50	18	22.0%
\$51 to \$100	11	13.4%
\$101 to \$150	6	7.3%
More than \$150	4	4.9%
More than \$500	36	43.9%
<b>Totals</b>	<b>82</b>	<b>100%</b>

More than 40% of respondents said they would be willing to pay more than \$500 for a vaccine to protect their child from a rare but serious disease. Just over one-third said they would be willing to pay up to \$100 for such a vaccine. Nine percent said they would not be willing to pay for the vaccine.

One quarter of the respondents said that price or cost of a vaccine should matter very much when it comes to recommending the vaccine for all children. Another third said it should matter somewhat, but not in the top three factors considered. Forty percent of the respondents said no price or cost is too much when it comes to preventing disease or illness.

# Appendix C—Individual Meeting Summaries

## Chicago, IL—July 21, 2011

<b>Question:</b> How much should the cost or potential cost of a vaccine matter when it comes to recommending its use for all infants or children? (multiple choice)		
<b>Response options</b>	<b># Responses</b>	<b>%</b>
Very much — it should be one of the top two or three factors used in determining whether a vaccine should be recommended for all infants or children	22	24.7%
Somewhat — it should be taken into account but shouldn't be one of the top two or three factors considered	31	34.8%
Not at all — no price or cost is too much when it comes to preventing disease or illness	36	40.5%
<b>Totals</b>	<b>89</b>	<b>100%</b>

One-quarter of the respondents said that price or cost of a vaccine should matter very much when it comes to recommending the vaccine for all children. Another third said it should matter somewhat, but not in the top three factors considered. Forty percent of the respondents said no price or cost is too much when it comes to preventing disease or illness.

<b>Question:</b> Which characteristic is most likely to make you want to recommend a new vaccine? (multiple choice)		
<b>Response options</b>	<b># Responses</b>	<b>%</b>
It involves few doses (i.e., 1 or 2)	3	3.5%
It helps prevent a disease or illness that, while rare, is often very severe	42	49.5%
It is very cost-effective — that is, it prevents disease at a relatively low overall cost	20	23.5%
It provides protection for a long period of time	20	23.5%
<b>Totals</b>	<b>85</b>	<b>100%</b>

Preventing a rare but severe illness was chosen by nearly half of the respondents as the characteristic they would rely on to decide whether to recommend a new vaccine. One quarter of the respondents said low cost was the most important characteristic, and another one quarter said that protection for a long time was the characteristic they would follow.

After the third set of polling questions, the participants discussed the results. Their statements included the following:

- Surprised at the results. For my own child I would do anything — but not sure where the money would come from.
- The number of doses matters— multiple doses difficult with challenges with access to health care, especially difficult for transient.
- Should be a cost or policy that encourages manufacturers to keep costs down. Cost does matter.
- If the vaccine is not recommended, people won't have the opportunity assess the risk for themselves and make a decision about vaccination

# Appendix C—Individual Meeting Summaries

## Chicago, IL—July 21, 2011

- If FDA has approved it, I want access to it! I want to make the choice to get it. I want access to vaccines if I want them.
- These are moral questions. The questions should be worded in a way that that is understood. If I am having a moral decision, make sure these questions are clear. What does “rare” mean?
- How much more in taxes are you willing to spend to support CDC? Budgets at federal and state levels are constrained.
- This saves lives, and I would spend the money to protect them.
- I want to know how many children are protected by getting vaccinated and how many get sick from vaccines.
- Herd immunity is an issue. I choose not to get a vaccine, and there is an impact from that choice. I would be willing to get vaccinated if I knew I was helping to protect others. I never thought about it that way before.
- Affordability is important — lives are at stake. Kids will die. This is not OK.
- Is there research on the combination of these vaccine and their side effects?
- Those who have money should pay for the vaccine; the government needs to assist those who can’t pay
- Are there vaccines that can be removed from the schedule? Can that create more money for research and development of new vaccines?
- I have diabetes; it runs in my family. I want to work to prevent this and protect my children from this, and put resources towards diabetes and ways to prevent it.

### Final Question

<b>Question:</b> Which recommendation option facing the ACIP and CDC is most in line with your beliefs and values? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Add to the infant/childhood immunization schedule; recommend all children be vaccinated	75	86.2%
No ACIP or CDC recommendation but add to the Vaccines for Children Program	7	8.0%
No ACIP or CDC recommendation and don’t add to the Vaccines for Children Program	5	5.8%
<b>Totals</b>	<b>87</b>	<b>100%</b>

A large majority favored adding the vaccine to the schedule. Eight percent would not make a universal recommendation but would include the vaccine in the Vaccines for Children Program. Just less than six percent of those who participated in the polling would neither include the vaccines in the infant/childhood schedule nor add the vaccines to the VFC Program. A post-polling discussion produced these comments:

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

### **Open Comment Period**

- There is low prevalence of this disease in the United States, high elsewhere. How does our recommendation limit the vaccine availability worldwide? I care about what happens worldwide. We are a rich, wealthy nation. Want to make sure rest of the world has access.
- I work in a community health center. We have low immunization rates because there is not a primary care provider. There may be a high overall vaccination rate overall in the country, but WE are struggling with immunization rates in my area, the west side of Chicago.
- Access is important to me. Depending on the recommendation, it could limit access. Access is very important to me.
- The recommendation needs to be made so that everyone has access to this vaccine. Choice matters, and you want the choice.
- It is important to share concerns about access and choice. Patients and doctors should have the choice to talk about this vaccine. The decision should be made on that level, not by the government. What implications does this have on future vaccines, future life-saving drugs and vaccines?
- We have to be careful to not pit choices against each other — entitlement programs for vaccination.
- Do not even use the permissive category. Make this mandatory. We are confused by permissive recommendations (said by pediatrician).

### **Small Group Discussion**

In an effort to allow participants to more fully delve into the issues, participants engaged in an hour long deliberation with a small group of participants (7 to 12 per group). This conversation was led and moderated by a small group facilitator. Groups were instructed to discuss the questions below and freely share opinions with one another; reaching consensus was not a goal of the group discussions. Themes which emerged from these small group deliberations included the following (*comments in italics from Spanish-speaking small groups*):

#### **Question 1: What are your thoughts related to the health threat posed by meningococcal disease to infants and young children?**

- It is rare, but also as “real and devastating.”
- The disease appears initially as the flu, why it is a serious threat. You will not know you have it until it’s too late. Initial diagnosis is not included in cause of death.
- No child should be allowed to die because of lack of vaccination.
- *It is a significant threat because of the seriousness even though the number people affected is low.*
- *Some participants had never heard of this disease before today.*
- *It is scary to see children get sick so quickly.*
- The threat will be greater because of globalization.
- Scary! Unexpected, real threat, can happen at any age, no treatment by vaccine.
- Very severe but does not have the B serotype; will the one-in-a-million adverse events outweigh the risk of the disease?
- A friend lost a baby and incurred a lot of expense. If the disease is preventable, then prevent it.

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

- Impressed by low number of deaths from meningococcal versus other causes of death.
- Vaccine is an easy fix to prevent meningitis-related deaths.
- Some participants questioned the validity of the statistics on the number of cases. They seem to believe that the numbers are higher.
- Need more statistics: demographics, urban/rural.
- Need more information about adverse reactions and other side effects.
- Doctors are not educated to diagnose or treat this disease.
- Prenatal educators would be able to talk to parents about the vaccine.
- The vaccine now does not have high enough efficacy to justify investment or implementation.
- More money should be spent pursuing a vaccine that also covers B serotype.
- Education is the key.
- Educate college students about the availability of the vaccine.
- More aware of the disease in young children and young adults.
- *It is a good vaccine, people should know about it.*
- *Need a national educational effort.*
- *We had we not heard about this until this meeting?*
- *People need to hear from providers and television about symptoms.*
- *Important for people to know it causes death and incapacitation.*
- *Images made an impact.*
- Make public aware of health risks.
- *It has to be priced to be affordable — if I cannot afford it, why bother?*
- Should be available to those who cannot afford it.
- *It should be available to adults.*

### **Question 2: What are people’s general thoughts and assessments regarding these new vaccines?**

- These new vaccines are a good thing, sounds like they are very safe.
- Since B serotype is not covered — there could be confusion in the future when the B becomes available.
- Concern they will not develop this vaccine until the B serotype becomes available.
- Benefits of prevention outweigh the risks.
- Good idea – as long as there are no high side effects.
- Allergic reactions possible?
- Need to hear more about the complications.
- Concerned about side effects.
- FDA approved, so we know it is safe.
- *Favor the vaccine after hearing about fewer doses and highly effective vaccine that lasts.*
- *Concern about long-term side effects from vaccine.*
- *It is good that there is prevention, people won’t become sick — prevent epidemics, avoid pain.*
- *I wish I could get it today for our kids.*

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

- May be a tipping factor of too many vaccines, the anti-vaccine people getting people to not vaccinate.
- Parents should have choice.
- It should be mandatory / available.
- Supportive of the vaccine but worried that parents will complain about the number of shots.
- Hesitant parents can be encouraged through education.
- *Education should start in schools.*
- Main concern is cost and access.
- Minority communities need access.
- As new vaccines are developed, they will naturally be more expensive.
- *Not everyone has access due to cost.*
- Recommendation is crucial.
- If it is not recommended, it may not be available to the public.
- Public education needed; health professionals also. People want information from their physicians.
- Information must be available at health centers, organizations, throughout community.
- *Could it be made available to adults and elderly?*

### **Question 3: What should or does CDC need to take into account when it comes to making recommendations related to these vaccines?**

- I would want my doctor to tell me about it, the sooner the better; educate providers and parents.
- A combination is highly favorable.
- The number of shots that are recommended, and at which intervals.
- The number of doses is not important, should not be a factor.
- Ensure that educational materials are available in many places and many languages.
- Education about the disease — the public is not aware of the prevalence in the younger years.
- Concern that patient/parent is not educated fully.
- There should be more focus on the doctor/patient relationship; not all doctors have good conversations with patients.
- Make sure people have access and choice.
- Choice yes, but take into account the community immunity.
- If it is preventative, it should be recommended.
- Chance of any child getting meningitis could be 1 in 2 million.
- *Should be recommended without considering adverse effects.*
- *Not worried about the number of shots.*
- *Doctors should educate their patients.*
- Anecdotal information about side effects; consider scientifically documented consequences of the vaccine.
- Should determine whether the side effects are more common than the disease.
- What are social implications of not vaccinating?
- Concerns about adding it to the schedule.

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

- The vaccination schedule should be better explained.
- Medical staff members would like a simpler vaccine schedule to distribute to the public.
- The public is skeptical.
- Trade-off between cost-effectiveness and long-term effect on patients.
- Trade-off between cost effectiveness and the patient making his own decision.
- Talk to pharmaceutical companies about actual costs and distribute first to low-income families.
- It should be affordable.
- Take into account the costs for people in poorer communities.
- Know how treatable the disease is.
- Bigger issue is the prevention of disease in general: disease, deaths, and consequences.
- Do not look at just the rarity, but also severity.
- Severity of consequences of the disease.
- Speed of onset.
- Take effectiveness into account.
- *Even if one human life is at risk, the vaccine should be administered.*
- *You cannot put a price on life.*
- *If a child were going to die, you would do whatever it takes.*
- *Vaccination would save the family.*
- *If it does not happen to you, it will happen to someone in your family sooner or later; you have to talk about it.*

### **Question 4: Does, or should, the price of a vaccine or the overall cost of an immunization recommendation matter, when it comes to decisions about how to use new vaccines?**

- Issue of cost is a multilayered issue — accessibility, retention.
- No, it should not be a factor.
- Cost is a factor, and it should be recommended.
- Keep it in consideration when recommendation is made.
- Track the costs and monitor in the future.
- Morally, cost should not matter.
- Should not be a factor in the recommendation; each individual parent can make a decision whether to vaccinate.
- Yes, it should matter. If it is recommended it might be more affordable to the public and covered by insurance.
- If it is not recommended, people might not know it is available.
- It could be recommended, but not aggressively.
- It all comes down to the “recommendation.”
- It should be accessible.
- Costs should fall with recommendation, with dosage amounts and as demand increases.
- Pharmaceutical companies have brought vaccines to market at high cost; we should not now say that it is “too expensive.”

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

- All costs count; we are in a national financial crisis.
- Quotable: “Sure, you can tell me how much it costs, but it’s still a life and it’s worth it.”
- Participants feel cost should not matter, but in the real world their opinions do not matter.
- If there is a cost issue, make the wealthy pay and subsidize the vaccine for the poor (sliding scale).
- *Price is important; everybody should be able to afford it.*
- *A life is a life — equal access for all.*
- *Pharmaceutical companies should give poor people a break.*
- *If it helps save any kids, cost should not be a factor, either as an individual or public/government cost.*

### **Question 5: What option or options would you support most if providing input to the ACIP and CDC?**

#### **Recommended with (below options)**

##### Overall strong support among groups

- All children should be vaccinated.
- With more combination vaccines.
- Freedom of choice / no mandate.
- Access to health care.
- Unanimously agreed.
- Because of education and access.
- Routine vaccination results in a mandate.
- Added responsibility on providers, government to educate people.
- Need for insurance coverage.
- To avoid morbidity and mortality.
- *Choose the vaccine over the danger of an adverse effect.*
- *I trust it is safe; there are more positive effects than negative.*
- *Contagiousness is a factor - every child can be affected.*
- *Participants from countries that had experienced public health crises thought the idea of not getting vaccinated was unthinkable.*

#### **Permissive with (below options)**

- Would not support No Recommendation, as it does not support saving lives, prevention, or availability.
- No recommendation or VFC only.
- Lack of information about the B serotype that is not protected.
- If it is not recommended, parents will not know about it; then there will be no educational effort and insurance will not pay for it except if it is covered by VFC.
- Leave it up to the doctors but add to VFC.
- Worried that the politics of cost would have the tea party take away the VFC program.
- Doctor has to decide about whom to give the vaccine.
- OK to add to the schedule; vaccine is better than the disease.

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

### **Question 6: Are efforts like this community meeting a good idea when it comes to developing immunization recommendations?**

- Concern about the cost of the community meetings.
- Yes, but costly with the stipends.
- Glad the community input is being taken.
- Should be held more often.
- Yes, and also can try social media / twitter.
- Yes, transparency in decision-making process.
- Best way to reach public — more promotion of the meetings.
- Yes, participants truly thought their opinions were important.
- Yes, informative.
- Should invite anti-vaccine people.
- Yes, important for policy development.
- Uncomfortable, worthwhile discussion.
- Consider mailings to get public opinion.
- Yes, I am more informed and got to give my input.
- Yes, but opinions need to be listened to; group wanted decision makers to be aware of these comments.
- *Yes, should be repeated; public input should be taken into consideration.*
- *Health fairs, schools, day cares should all have meetings on this topic.*
- *Focused meeting, did not jump around.*
- *Happy about being included in the process, that is not like experience in the home country.*
- CDC should spend effort on educating the public on the safety of vaccines.
- More education needed for doctors, nurses, and public.
- Educational.
- *I will be sharing information with my neighbors, friends, and community; nobody at our table knows anybody affected by meningitis.*
- *The vocabulary was challenging.*
- *Should have meetings on other diseases — fibromyalgia, diabetes, arthritis.*
- Boundaries were set and the meeting was not used as a platform for pro- or anti-vaccine movements.
- Slanted meeting advertisement / slanted presentations.
- Some questions were leading to specific answers.
- Meeting was moving in a certain direction.
- Meeting should be objective.
- Important if you want compliance.
- *Good facilitators.*
- If the FDA approves a vaccine, the CDC should go ahead and recommend it.
- Should forget the permissible category and recommend all vaccines approved by FDA.
- Dialogue is good, but we should not be making recommendations.
- Quotable: “No, I do not want this little pow-wow to have an effect on recommendations. They should be based on science and data.”

# Appendix C—Individual Meeting Summaries

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## *Chicago, IL—July 21, 2011*

### Chicago Participant Profile

The most represented age group at the Chicago meeting was 31 to 50 years (47.3%). The second most represented age group was 18 to 30 years (27.3%), and closely behind that group was 51 and above (25.4%).

Age range	Percentage
18-30 years	27.3%
31-50 years	47.3%
51 and above	25.4%

While a majority of participants were women (85%), only 15% were men.

Sex	Percentage
Male	15.3%
Female	84.7%

A majority of participants (40.5%) identified themselves as Hispanic or Latino. The remaining participants identified themselves as White (38.8%), Black (or African American) (11.2%), Asian or Pacific Islander (6.0%), Other (2.6%), and Mixed Race (.9%).

Race/Ethnicity	Percentage
Asian or Pacific Islander	6.0%
Mixed Race	.9%
Black (or African American)	11.2%
Hispanic or Latino	40.5%
White	38.8%
Other	2.6%

*Note: Some participants identified themselves as more than one race or ethnicity*

A majority of participants (33.6%) are parents or guardians of children 18 years old or younger. On the other hand, 38.8% of participants are not parents or guardians of a child 18 years old or younger. Participants have younger children as well: 17.3% have a child 6 years old or younger, and 10.3% have a child 2 years old or younger.

# Appendix C—Individual Meeting Summaries

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## ***Chicago, IL—July 21, 2011***

<b>Are you a parent/guardian of a child 18 years old or younger?</b>	<b>Percentage</b>
My child is 2 years old or younger.	10.3%
My child is 6 years old or younger.	17.3%
My child is 18 years old or younger.	33.6%
I am not a parent/guardian of a child 18 years old or younger.	38.8%

*Note: Not all participants chose to respond on their parental status. A few participants selected more than one category*

### **Meeting Arrangements and Recruitment**

- The Keystone Center worked with local hosts to identify, evaluate, and obtain venues; secure the required audio-visual equipment; and identify meal options. The Chicago meeting was conducted at the Holiday Inn O’Hare. The Chicago Area Immunization Campaign (CAIC) arranged lunch for the participants.
- The Chicago team comprised the Chicago Area Immunization Campaign, the Chicago Department of Public Health, and the Illinois Department of Public Health. The team, coordinated by CAIC Director Lisa Kritz, developed a plan to recruit participants that used existing, well-coordinated relationships among agencies. CAIC distributed recruitment flyers to its extensive contact lists, which resulted in a strong turnout. Shortly before the meeting, contacts in the Spanish-speaking community resulted in a substantial turnout from that community.

### **Distinctive Features of the Meeting and Lessons Learned**

Half of the participants in the Chicago meeting were Hispanic, and Spanish-language interpretation was provided. There was insufficient time between the Chicago meeting (Thursday) and the subsequent meeting in Denver the following Monday to identify or implement any revisions.

# Appendix C—Individual Meeting Summaries

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## ***Denver, CO—July 25, 2011***

### **Welcome**

The meeting participants were welcomed by Margaret Huffman, ND, RN, Community Outreach Program Manager, Colorado Immunization Program, Colorado Department of Public Health and Environment (CDPHE).

### **Introduction**

Glen Nowak, Ph.D., Senior Advisor, National Center for Immunization and Respiratory Diseases, introduced the topics for the day and proposed these three questions for discussion:

- Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?
- If you were giving advice to CDC about what factors should be given high priority when it comes to deciding how to use a new vaccine, what would your advice be?

What do you think are the conditions, situations, characteristics that would warrant a broad or widespread use of a new vaccine (for example, a recommendation that all children should get vaccinated)?

### **Polling Results and Plenary Discussion**

The discussion began with questions about the future of vaccine research and development, “Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases they should consider creating vaccines for, what would those be?”

Their responses included:

- Respiratory syncytial virus (RSV)
- Cancer
- Type B meningococcal disease
- Nicotine addiction
- Depression
- Alzheimer’s disease
- Chlamydia
- Gonorrhea
- HIV/AIDS

The reasons for selecting these included:

- Global impact
- Severity
- Frequency and severity
- High cost of the burden of disease
- Desire to protect children from disease, avoid deaths
- Emotional distress of the person struggling with the disease and their family

# Appendix C—Individual Meeting Summaries

## Denver, CO—July 25, 2011

Participants placed an emphasis on the desire to protect children, as well as high risk populations. Participants also want vaccines for the aforementioned diseases to ensure a high quality of life for people of all ages.

### Polling Question Set 1

Scientists and companies are constantly working to develop new vaccines to prevent illness and disease. If you were giving advice to scientists and others about the kinds of illnesses and diseases that they should consider creating vaccines for, what would those be?

<b>Question:</b> Which type of disease do you think should be given priority when it comes to developing new vaccines? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Affects lots of people but most illness is not severe	0	0%
Relatively rare, but illness is often severe	17	54.8%
They should be given equal priority	14	45.2%
<b>Totals:</b>	<b>31</b>	<b>100%</b>

Slightly more than half of the participants indicated that a relatively rare, but severe disease should be given priority for vaccine development. The rest of the participants indicated that they should be given equal priority. None selected a disease that affects a lot of people but is not severe.

<b>Question:</b> Thinking about vaccine development, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make an investment in a vaccine a good idea? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
1 child out of 100	6	18.7%
1 child out of 1,000	6	18.7%
1 child out of 10,000	8	25.0%
1 child out of 100,000	6	18.7%
1 child out of 1,000,000	6	18.7%
<b>Totals</b>	<b>32</b>	<b>100%</b>

One-quarter of the participants indicated that an illness that occurs in 1 child out of 10,000 would be an appropriate threshold for investment in a vaccine. The remaining participants were equally divided in their choice between all other options.

# Appendix C—Individual Meeting Summaries

## Denver, CO—July 25, 2011

After the first two polling questions, the participants discussed the results and their values. Their statements included the following:

- When I vote in the electronic polling, I think about different infection rates for different diseases in the U.S. as compared to other nations. Even if children in the U.S. do not die from a disease, children in other countries do.
- Parents in the U.S. have choices about vaccination that parents in other countries do not. Therefore, I value affordable vaccines.
- My concern is that once the ACIP recommends a vaccine, I do not get a choice whether to vaccinate. I do not like that I do not get a choice whether to vaccinate without a negative repercussion (some children get excluded from schools if they are not vaccinated); in my opinion, this is un-American.
- I support choice and informed consent in regards to vaccines.
- The public is not aware of adverse reactions to vaccines and government compensation.
- I lost my child to a vaccine-preventable disease; I wish I would have known about the vaccine in advance.

### Polling Question Set 2

If you were giving advice to CDC about what factors should be given high priority when it comes to deciding how to use a new vaccine, what would your advice be?

<b>Question:</b> If you were giving advice to scientists and others about the characteristics, qualities or features that a new vaccine should have, what would your advice be? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Protects many	11	36.7%
Protects for a long time (e.g., at least 10 years)	0	0%
Requires few doses (e.g., 1 or 2)	0	0%
Few side effects	5	16.7%
Is combined with one or two other recommended vaccines	1	3.3%
Protects against a disease that while rare, usually brings severe illness	13	43.3%
<b>Totals</b>	<b>30</b>	<b>100%</b>

When asked to choose one important quality, feature, and characteristic of new vaccines, almost half of the participants selected protects against a disease that, while rare, usually brings severe illness. Protecting many and few side effects followed with 36.67% and 16.67%, respectively.

# Appendix C—Individual Meeting Summaries

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## *Denver, CO—July 25, 2011*

<b>Question:</b> What is the minimum acceptable level of protection that a new vaccine would need to provide?		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
It should protect at least 25 of every 100 people vaccinated	4	12.9%
It should protect at least 50 of every 100 people vaccinated	1	3.2%
It should protect at least 65 of every 100 people vaccinated	8	25.8%
It should protect at least 75 of every 100 people vaccinated	8	25.8%
It should protect at least 90 of every 100 people vaccinated	10	32.3%
<b>Totals</b>	<b>31</b>	<b>100%</b>

About one-third of participants stated that no less than 90% effectiveness is adequate. Participants were divided 8-and-8 between 65% and 75% effectiveness.

After this set of polling questions, the participants discussed the results and their values. Their statements included:

- Significant side effects to a vaccine are unacceptable.
- I want a vaccine to protect against a serious, but rare disease because I want to avoid lifelong physical injury from a disease.
- I want to protect people from a disease in order to prevent the spread of the disease.
- I want few and very mild side effects in a vaccine.
- Some of the factors I value are not presented in the questions, such as cost. I value risk-benefit analysis.
- I have read and heard about the connection between autism and vaccines. I am concerned that we do not have a strong understanding of the long-term adverse effects of vaccines.
- It is important to consider the economic impact of a disease on a family and community.

### **Polling Question Set 3**

What do you think are the conditions, situations, characteristics that would warrant a broad or wide-spread use of a new vaccine (for example, a recommendation that all children should get vaccinated)?

# Appendix C—Individual Meeting Summaries

## Denver, CO—July 25, 2011

<b>Question:</b> Thinking about vaccine recommendations, for you, how many infants and children would need to get a severe illness from the disease in a typical year in the U.S. to make it a good idea that all children be vaccinated? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
1 child out of 100	7	22.6%
1 child out of 1,000	6	19.4%
1 child out of 10,000	6	19.4%
1 child out of 100,000	5	16.0%
1 child out of 1,000,000	7	22.6%
<b>Totals</b>	<b>31</b>	<b>100%</b>

When asked about how many severe illnesses in a year would warrant vaccination, participants were nearly evenly divided in their responses.

<b>Question:</b> If you had to pay for a vaccine that protected your child from a rare but serious disease, what would you be willing to pay out of pocket? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Zero	0	0%
Up to \$50	2	6.9%
\$51 to \$150	8	27.6%
\$151 to \$250	6	20.7%
\$251 to \$500	3	10.3%
More than \$500	10	34.5%
<b>Totals</b>	<b>29</b>	<b>100%</b>

More than one-third of participants indicated that they would be willing to pay more than \$500 for a vaccine. Nearly half of the participants chose a mid-range value.

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## Denver, CO—July 25, 2011

<b>Question:</b> How much should the cost or potential cost of a vaccine matter when it comes to recommending its use for all infants or children? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Very much -- it should be one of the top two or three factors used in determining whether a vaccine should be recommended for all infants or children	2	6.7%
Somewhat – it should be taken into account but shouldn't be one of the top two or three factors considered	16	53.3%
Not at all – no price or cost is too much when it comes to preventing disease or illness	12	40%
<b>Totals</b>	<b>30</b>	<b>100%</b>

More than half of the participants indicated that the cost of vaccination should not be one of the top two or three considerations in whether or not to recommend the vaccine. Only two of the 30 participants indicated that cost is a very important consideration.

<b>Question:</b> Which characteristic is most likely to make you want to recommend a new vaccine? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
It involves few doses (i.e., 1 or 2)	0	0%
It helps prevent a disease or illness that while rare, is often very severe	21	70%
It is very cost effective – that is, it prevents disease at a relatively low overall cost	4	13.3%
It provides protection for a long period of time	5	16.7%
<b>Totals</b>	<b>30</b>	<b>100%</b>

Most participants indicated that the characteristic most likely to make them want to recommend a vaccine is its ability to prevent a rare but serious illness. The remaining participants were evenly divided between cost-effectiveness and long-term protection.

After these polling questions, the participants discussed the results and their values. Their statements included the following:

- I compare the cost of a vaccine to the cost of treating a disease.
- If everyone is vaccinated against a disease, everyone is protected. The cost of a vaccine is worth it to me because it saves lives.
- Wyoming used to be a universal vaccine state. Now, Wyoming is a universal select state, and the meningococcal vaccine is not included in the program. As a result, providers in the state are not offering the vaccine because they do not want to pay for it up front. Wyoming is hoping to return to status as a universal vaccine state, but it is a complicated budgetary issue.
- We need to weigh all economic costs of a disease (school closings, individuals missing work, etc.)

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against the cost of the vaccine.

- I believe we should only vaccinate children who are more likely to contract the disease.

### Final Question

<b>Question:</b> Which recommendation option facing the ACIP and CDC is most in line with your beliefs and values? (multiple choice)		
<b>Response options</b>	<b># of Responses</b>	<b>%</b>
Add to the infant/childhood immunization schedule; recommend all children be vaccinated	23	79.3%
No ACIP or CDC recommendation but add to the Vaccines for Children Program	4	13.8%
No ACIP or CDC recommendation and don't add to the Vaccines for Children Program	2	6.9%
<b>Totals</b>	<b>29</b>	<b>100%</b>

Nearly 80% of participants said adding the vaccine to the schedule would be most in line with their values.

### Open Comment Period

- National Meningitis Association (NMA) board member, and mother of a child who had meningitis, described NMA's mission: to educate the public about meningitis and that the disease is vaccine-preventable. NMA supports victims of the disease and advocates for legislation that aligns with our values throughout the country. NMA also provides information to help parents make a choice on whether to vaccinate.
- President of Meningitis Angels, who lost her child to meningitis, appreciated being able to observe these public meetings and talk with parents that have views other than her own. She supports a full recommendation of the vaccines to give all children equal access to the vaccine, and to ensure public funding for education. She wants the ACIP to prioritize what is best for the nation's children over economic concerns.

### Small Group Discussion

In an effort to allow participants to more fully delve into the issues, participants engaged in an hour long deliberation with a small group of participants (5 to 7 per group). This conversation was led and moderated by a small group facilitator. Over the course of an hour, the questions below were discussed and deliberated upon by participants in the small group setting to allow participants to further engage in a more in-depth discussion of these issues. Groups were instructed to discuss the questions

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## ***Denver, CO—July 25, 2011***

below and freely share opinions with one another; reaching consensus was not a goal of the group discussions. Themes which emerged from these small group deliberations included the following:

### **Question 1: What are your thoughts related to the health threat posed by meningococcal disease to infants and young children?**

- The disease is severe with devastating symptoms, and unpredictable; it can affect anyone at any age.
- The disease is scary because doctors cannot stop the progression of the disease.
- I fear the ease of transmission of the disease.
- The threat of the disease is big because CDC cannot predict future infection rates.
- The decrease in quality of life after surviving the disease may not be worth living.
- Why is the disease more prevalent in other countries compared to the U.S.? Can American travelers carry the disease into the U.S. and spread the disease?
- Need for increased awareness of meningitis to decrease the perception that “it can’t happen to me.”

### **Question 2: What are people’s general thoughts and assessments regarding these new vaccines?**

- I am concerned about the unknown cost of these vaccines, especially since our current health care system is already “overburdened.”
- The vaccines are not cost-effective.
- Money should be invested on developing better vaccines.
- Vaccine safety (ingredients and adverse effects).
- Vaccine efficacy.
- There is a lack of public information about vaccine risks; I want more science-based facts about the vaccine.
- I would prefer to suffer from an adverse effect of the vaccine than die from the disease.
- I am concerned that there are already too many vaccines on the schedule; they are hard for parents to track, and traumatic to witness as their children get injected with so many shots.
- Herd safety should be a big component when deciding whether or not to vaccinate the public.
- Overall preference for combination vaccines, but if a child has an adverse effect to the vaccine, how can you determine which vaccine caused the adverse reaction?
- Combination vaccines mean fewer doctor visits and painful shots.
- I would prefer an oral vaccine.
- If an infant gets vaccinated against meningococcal disease and the infant (later on) develops the disease’s symptoms, could the doctor fail to identify the symptoms as meningococcal disease?
- Widespread vaccination in the U.S. may help reduce the number of cases of disease in other countries.
- The public should have the option whether to vaccinate.

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## ***Denver, CO—July 25, 2011***

### **Question 3: What should or does CDC need to take into account when it comes to making recommendations related to these vaccines?**

- Commitment to public education about the disease and vaccines (ingredients, adverse effects, the option not to vaccinate)
- Prevalence of disease
- Severity of disease
- Duration of disease
- Potential for family devastation — highest priority
- The feedback from these public meetings

### **Question 4: Does, or should, the price of a vaccine or the overall cost of an immunization recommendation matter when it comes to decisions about how to use new vaccines?**

- Cost of vaccine (development, transportation, purchase price) matters.
- Adverse effects of vaccine.
- Long-term costs of disease to families and communities (hospital, rehabilitation services, mental health impact, productivity loss of child and parents) should be considered.
- Cost of vaccination must be balanced against other health concerns and monetary demands within the government.
- Cost should not matter morally, but in reality, it does.
- Cost should not matter in comparison to the benefit of saving lives.
- The cost of vaccination should not matter since the cost of vaccination would most likely be less than the cost of disease; proactive health care is cheaper than reactive care.
- Cost should not matter since the cost of the vaccine will decrease over time.

### **Question 5: What option or options would you support most if providing input to the ACIP and CDC?**

#### **Full recommendation**

- Importance of funding for public education.
- VFC funding to ensure equal access for all children.
- A full recommendation is the only way the financial and public health investment in the vaccines will be worthwhile.
- If a vaccine can save lives, it should be used.
- Since scientists cannot predict who is at risk for disease, a full recommendation is important.
- A permissive recommendation would send mixed messages to parents.

#### **Permissive recommendation with VFC funding**

- Overall belief in personal choice, but the vaccine should be available for parents who want it, regardless of ability to pay.
- VFC funding may help make the opt-out option less taboo for parents.

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## **Denver, CO—July 25, 2011**

### **Permissive without VFC funding**

- Based on importance of personal choice.
- Need for more research on adverse effects of these vaccines.

### **Question 6: Are efforts like this community meeting a good idea when it comes to developing immunization recommendations?**

- Yes, I appreciate being able to have my voice heard.
- Yes, I believe in public engagement.
- Yes, it was valuable to hear a diverse range of opinions, as well as the experiences of those affected by the disease.
- Yes, it is important for families affected by the disease to hear opinions that are different than their own.
- As consumers of the vaccines, we should be able to voice our opinions to the CDC and ACIP. There needs to be more of a balance of power between consumers and vaccine manufacturers.
- Yes, it was valuable to learn about such a complex issue.
- How much impact will these meetings really have on the ACIP's decision?
- No, a survey would have yielded similar results.
- Did the CDC learn anything today?

### **Other themes which emerged from small group discussions:**

- Overall perception that the meningococcal vaccines are not as effective as other vaccines currently on the schedule.
- Overall frustration that the new vaccines do not protect against Serogroup B.
- Public education about the disease and vaccines, as well as VFC funding, were the primary reasons for support of the full recommendation.

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## **Participant Profile**

Participants of different ages, ethnicities and parental status attended the meeting:

Nearly half of the participants (44.7%) were between the ages of 31 and 50. Participants aged 51 and above represented 38.3% of the group while participants between the ages of 18-30 only represented 17.0% of the group.

<b>Age range</b>	<b>Percentage</b>
18-30 years	17.0%
31-50 years	44.7%
51 and above	38.3%

An overwhelming percentage of participants were women (81.6%). Only 18.4% of the participants were men.

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## ***Denver, CO—July 25, 2011***

An overwhelming percentage of participants were women (81.6%). Only 18.4% of the participants were men..

<b>Sex</b>	<b>Percentage</b>
Male	18.4%
Female	81.6%

A majority of participants were white (81.3%). Only a few participants reported their ethnicities as Asian or Pacific Islander, Mixed Race, Black, Hispanic/Latin or Other.

<b>Race/Ethnicity</b>	<b>Percentage</b>
Asian or Pacific Islander	8.3%
Mixed Race	4.2%
Black (or African American)	2.1%
Hispanic or Latino	2.1%
White	81.2%
Other	2.1%

*Note: Not all participants chose to report their race/ethnicity*

About half of the participants (49.1%) are not parents or guardians of a child under 18 years old. The other half has children of varying ages: 13.2 percent of participants have a child 2 years old or younger, 11.3 percent have a child 6 years old or younger, and 26.4 percent of participants have a child 18 years old or younger.

<b>Are you a parent/guardian of a child 18 years old or younger?</b>	<b>Percentage</b>
Yes, my child is 2 years old or younger.	13.2%
Yes, my child is 6 years old or younger.	11.3%
Yes, my child is 18 years old or younger.	26.4%
No, I am not a parent/guardian of a child 18 years old or younger.	49.1%

*Note: Not all participants chose to respond on their parental status. A few participants selected more than one category.*

# Appendix C—Individual Meeting Summaries

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## ***Denver, CO—July 25, 2011***

### **Meeting Arrangements**

- The Keystone Center worked with local hosts to identify, evaluate, and obtain venues; secure the required audio-visual equipment; and identify meal options. The meeting was conducted in the Mt Yale Conference Room at Children’s Hospital in Aurora, Colorado. The Colorado Department of Public Health and Environment and the Colorado Children’s Immunization Coalition arranged for meals to be provided for participants.
- The Keystone Center was responsible for identifying and recruiting facilitators and note takers. Keystone worked through networks at the Denver University’s Master’s Program in Conflict Resolution to obtain qualified and experienced individuals.
- Attendees were recruited through a variety of activities, beginning with the development of a list of more than 400 health care professionals, community groups, and agencies representatives. This list was developed in cooperation with the local hosts, who sent email blasts to the list twice during the recruitment process. Keystone identified a score of websites and social media avenues through which to disseminate the information, including the posting of meeting information on well-known blogs and mothers’ group calendars. Keystone followed up with phone calls to local mom groups, faith-based organizations, and cultural and community groups.

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #2 Summary

*Atlanta, GA, October 5, 2011*

### Meeting Objectives / Goals For Day

- Discuss key themes and findings from the four community meetings in Concord, Seattle, Chicago, and Denver
- Provide input regarding economic and resource factors/considerations related to immunization policy decisions
- Discuss use of stakeholder and public engagement

### Dr. Anne Schuchat, Director, NCIRD

Dr. Schuchat welcomed everyone and thanked them for lending their knowledge and perspective. She emphasized that NCIRD takes its mission seriously because immunization policy affects every family in the country. She said that ACIP issues are complex because they touch on different values. She hopes that this project was a good step toward strengthening the ACIP process, uncovering public values, and building public trust.

### Site Leader Reports

#### *Concord, NH*

The site leader for New Hampshire noted that the media continues to mention the public meeting even though no reporters attended, and that the meeting was seen as a major effort by both CDC and the health department. Meeting participants were pleased that CDC came out of Atlanta for this project. During the meeting, participants pushed back against making a decision through polling, and ACIP probably faces the same issue. Participants probably realized how hard it is for ACIP to make this decision.

#### *Seattle, WA*

The site leader said the meeting demonstrated that people want information about vaccines, about meningococcal disease, and about risk. She said public health officials were worried about how the day would unfold but discovered that the discussion was respectful and led to valuable connections between pro-vaccine and anti-vaccine participants. She reported that it was a complex discussion and that meeting participants seemed to be pleased that government was wrestling with the issue.

#### *Chicago, IL*

The site leader emphasized that the meeting attendees were all local stakeholders connected somehow to the immunization issue. She reported that at the outset participants did not have a clear understanding of the public health perspective, and expressed the importance of devoting time to putting the cost issue into context.

#### *Denver, CO*

The site leader stated that at the time of the meeting, meningitis had been in the news in Colorado because of a recent outbreak. She thought that this may have been one reason for the relatively low

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #2 Summary

*Atlanta, GA, October 5, 2011*

attendance; perhaps people thought that they had already been educated about meningococcal disease and did not feel the need to know more about it. Sixty-five registered for the meeting; 35 attended. She reported that there was a thoughtful discussion about the impact of adding a new vaccine to the immunization schedule. She stated that the meeting should have included more discussion about the cost of such a move. She concluded by saying that it is also important to have this discussion with private providers.

## Additional Observations from Site Meetings

- The meetings helped to educate the attendees, and it appears that participants are taking the discussion back to their communities and constituencies.
- The meetings gave vocal anti-vaccine participants, pro-vaccine participants, epidemiologists, and public health agency staff opportunities for meaningful discussion.
- Meetings seem to have changed the views of some who heard personal stories from those affected by meningitis.
- Those who are vaccine-hesitant stayed for the entire meeting and engaged in the dialogue.
- Much of the discussion focused on the range of choices ACIP/CDC can make and how those choices are interpreted and misinterpreted; recommending becomes mandating, a permissive recommendation gets interpreted as something less than endorsement, and there is confusion about the meaning of a permissive or a universal recommendation.
- These perceptions are linked to the fact that states take action to add mandates of one kind or another after the ACIP/CDC recommendation.
- The meetings also shone a light on the value of the parent-caregiver conversation about vaccines, the time constraints on that conversation, and the competition with other topics for that limited time.
- Vaccine-hesitant parents wanted to discuss their concerns with parents whose children had suffered from or died from meningococcal disease.
- The meetings did not attract the general public as much as stakeholders would have hoped.

## Presentation by the University of Pennsylvania Center for Bioethics

Prior to the small-group discussions, David Curry, executive director of the Center for Vaccine Ethics and Policy offered a set of questions for the stakeholders to consider as they completed their discussions.

He asked three questions:

1. Are values, social norms, and bioethics analysis forms of evidence?
2. How might one portray the available evidence and incorporate values?
3. How might one treat values, social norms, and bioethics in vaccine decision processes?

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #2 Summary

*Atlanta, GA, October 5, 2011*

He indicated that it is appropriate for decision makers to consider questions of autonomy, equity, access, justice, the demand dynamics of critics and advocates, program feasibility, implementation challenges, and cost in addition to more widely accepted considerations of risk, disease severity, cost-effectiveness, and the potential for adverse vaccine events. He offered this observation at the conclusion of this remarks: CDC/NCIRD/ACIP leadership could develop evidence-level approaches for capturing and presenting societal values, social norms, and bioethics analysis for potential use in ACIP vaccine recommendation decision-making.

### Small Group Discussion

#### **Cost**

Much of the public meeting time and a good deal of the small-group discussion during the stakeholders' meetings focused on whether and how to consider cost-effectiveness in reviewing the meningococcal vaccines. The meeting participants expected cost-effectiveness to be included in the data and expected that cost-effectiveness will be a factor in whether the vaccines are added to the infant immunization schedule, particularly given the pressures on state and federal budgets. No one suggested ignoring questions of cost-effectiveness.

However, some participants believe in separating ACIP's and CDC's roles, leaving ACIP to consider only the potential benefits of the vaccine and the target population, and leaving the cost-effectiveness analysis to CDC. Others expect that ACIP should be explicit in including cost-effectiveness in their analysis and, in order to accomplish the analysis carefully, needs to confront the question of a cost-effectiveness threshold or methodology that would be applied to all vaccines. The process of public and stakeholder review of the meningococcal vaccines has highlighted the need for a new and rigorous decision-making process for CDC that would apply a standardized cost-effectiveness analysis to the vaccine program decision.

Those who have been affected by meningococcal disease also offered a counterpoint to the economic analysis, pointing out that they, and many from the public meetings, believe that the possibility of preventing a vaccine-preventable disease and saving even one life warrants a full recommendation, particularly when the cost of treating one person affected by meningococcal disease can exceed \$1 million.

#### **Equity and Access**

The focus on cost-effectiveness prompted concerns that ACIP and CDC would focus too much attention on economic considerations. As a result, the small groups also focused on equity and access, with many stakeholders placing a high priority on access to new meningococcal vaccines for all children, whether through VFC or insurance. They felt that with the current ACIP options available, the only way to achieve this broad access would be with a universal recommendation. A permissive recommendation with VFC would create inequities, as only poor children would have access, assuming that insurance companies would not cover the vaccines.

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #2 Summary

*Atlanta, GA, October 5, 2011*

### *Refining ACIP's Options*

The stakeholders picked up where the public meeting participants left off in discussing the specific choices facing ACIP and CDC — whether to add the meningococcal vaccines to the childhood schedule (universal recommendation) or to make a permissive recommendation and, if permissive, whether to add them to the Vaccines for Children Program. The stakeholders echoed the advantages of a broader and more nuanced set of options than those listed above — for example, an option that would allow for broad education and access without making meningococcal vaccination routine for all children.

With the understanding that a universal recommendation drives education, promotion, and tracking, many would favor CDC action to disseminate information about meningococcal disease and the soon-to-be-licensed vaccines. They would favor efforts to get nurses, doctors, and other health care workers to discuss with their patients the risks of contracting meningococcal disease and the existence of the vaccines.

The stakeholder meeting participants also considered the public meetings' call for an education strategy that recognizes the increasing importance of parental choice. Some in the public meetings see the schedule as a decision made on their behalf and prefer to make their own choice. Some conflate CDC's placing a vaccine on the childhood schedule with state-level or school-district-level mandates; others see the distinction and don't conflate the immunization schedule with mandated vaccination and yet recognize that the childhood schedule is treated by many as if it were mandatory. The small-group discussion affirmed that the stakeholders are seeing these same attitudes and suggested the need to re-frame the CDC immunization schedule to make it clear that recommendations are not the same as mandates.

Another set of voices in favor of robust education about the vaccines come from those who have been personally affected by meningococcal disease. Many stated that they had no prior understanding of the severity of the disease and were not aware that it is vaccine preventable. For them, robust education about the disease and the vaccines are vitally important.

### **Final Comments**

After the small group discussion, the participants offered these observations:

- The process would have been stronger if a meeting had been held in the South, and if more of the general public would have participated.
- It has to be clear what this process means for ACIP — Are we shifting their role?
- The most value in this public engagement process was to the people who participated in the meetings. It would be hard to take the results of these meetings and distill them into broader actionable outcomes.
- These meetings should not be seen as a quantitative data gathering tool, but more as a qualitative

# Appendix C—Individual Meeting Summaries

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## Stakeholder Meeting #2 Summary

*Atlanta, GA, October 5, 2011*

tool and as a way for CDC to achieve transparency.

- This process should be rolled out more widely through state health departments, with CDC support.
- It is important to consider how the vaccination decision making process fits into the Affordable Care Act.
- ACIP needs a change-management perspective as it looks at changing the vaccination schedule.
- One participant stated that the prevalence of meningococcal bacteria and the low incidence of disease suggest natural herd immunity; there is a concern that a vaccine could disrupt this natural immunity. Other participants in the meeting disagreed with this conclusion.
- Parents facing the childhood vaccination schedule need to understand how devastating meningococcal disease is.
- It makes sense to vaccinate when one considers the high cost to individual families of treating the disease.

## Announcement

ACIP now webcasts its meetings live. The next meeting is October 25–26, 2012.

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

### NEW HAMPSHIRE RECRUITMENT ACTIVITIES

Prior to the meeting, the staff from the New Hampshire Immunization Program widely circulated a meeting invitation to their local and regional networks. They sent a press release to their media contacts, resulting in pre-meeting media coverage. Local newspaper advertising and a mailing to more than 1,700 health care providers in New Hampshire were also part of the recruitment strategy. The Keystone Center worked to recruit a diverse group of participants by reaching out by phone and email to more than 275 organizations and individuals, including the following:

#### Children and Education Groups

Concord Homeschool  
Children’s Alliance of New Hampshire  
Children’s World Learning  
Christian Home Educators of New Hampshire  
Discovery Village Early Learning Center  
Early Learning NH  
Elementary schools across the region (private and public)  
Epping Head Start  
Girls, Inc.  
Homegrown Explorers  
JBC Youth Group  
Kearsage Mountain Homeschoolers  
Lighthouse Homeschool Co-op  
Manchester Area Homeschoolers  
Merrimack County Child Advocacy Center  
New Hampshire Healthy Kids  
New Hampshire Homeschooling Coalition  
New Hampshire PTA  
New Hampshire Teen Institute  
Rockingham Head Start  
The Children’s Place and Education Center  
Youth Empowerment Services

#### Community and Civic Organizations

Alliance for Community Supports  
AmeriCorps VISTA Programs  
Boy Scouts  
Caring Community Network of the Twin Rivers  
Haitian Community Center of New Hampshire  
Latinos Unidos de New Hampshire  
League of Women Voters of NH

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

New Hanover County Community Action  
Rockingham Community Action  
YMCAs through New Hampshire  
Volunteer New Hampshire

### Faith-Based Organizations

Bethlehem Hebrew Congregation  
Jewish Federation of New Hampshire  
First Congregational Church, UCC  
Immaculate Heart of Mary Parish  
Manchester Christian Church  
New Hampshire Faith-Based Action Network  
St Marie Parish  
St Paul’s Episcopal Church  
Temple Beth Abraham  
Temple Beth Jacob  
Temple B’nai Israel  
Trinity Baptist Church

### Public Health and Medical Groups

Carroll County Coalition for Public Health  
Concord Feminist Health Center  
Concord Hospital Family Health Centers  
Families First Health and Support Center  
Foundation for Healthy Communities  
Health First Family Care Center  
Health and Safety Council of Strafford County  
Lakes Region Partnership for Public Health  
Mid-State Health Center  
New Hampshire Medical Society  
New Hampshire Pediatric Society  
New Hampshire State Board of Medicine  
New Hampshire School Nurses’ Association  
New Hampshire Voices for Health  
North Country Health Consortium  
Private providers across the state  
Red Cross  
The Dartmouth Institute for Health Policy and Clinical Practice

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

### Neighborhood and Parent Groups

Concord Moms Group  
La Leche League of NH – Concord  
Manchester NH MOMS Club  
Moms Club of Amherst  
Mothers of Preschoolers (MOPS) groups across the state  
Parent Links Group  
Parenting New Hampshire  
The Single Mom’s Survival Guide

### Other Groups and Organizations

New Hampshire Coalition for Vaccine Choice  
The Autism Society of New Hampshire  
Women in Government

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## SEATTLE RECRUITMENT ACTIVITIES

The outreach effort for Seattle included direct contact with Department of Health partners and affiliated organizations and staff, and a social media effort that included well-known bloggers, popular users of Twitter, and some Facebook postings. A news release resulted in news articles and generated a surge of registrations. Below is an extended list of contacts:

### Email Distribution List for Immunization Partners

Advanced Registered Nurse Practitioners (ARNPs)  
Bastyr Center for Natural Health  
Washington Osteopathic Medical Association (WOMA)  
Washington State Medical Association (WSMA)  
Washington State Hospital Association  
Washington State Nurses Association  
Washington State Parent Teacher Association (PTA)  
Washington State Pharmacy Association

### Email Distribution List

American Indian Health Commission of Washington  
Child Care Health Consultants  
CHILD Profile Advisory Group  
Coalition for Safety & Health in Early Learning  
Health Plan Immunization Quality Improvement Staff

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

Hepatitis B Coordinators  
Indian Health Service  
Local Health Immunization Coordinators and Leadership  
Portland Area Northwest Indian Health Board  
School & Childcare listserv  
School Nurse Organization of Washington  
State Board of Health  
Vaccine Advisory Committee (VAC)

### Blogs

Absolutely Bananas  
Bacon Is My Enemy  
Beast Mom  
Capitol Hill Parenting  
Confessions of a Psychotic Housewife  
Daring Young Mom  
G.P.S. Blog  
Green Lake Moms  
Happily Even After  
Kids & The City/Stop Screaming I'm Driving  
Little Moments That Matter  
Over-Caffeinated Dad  
Parenting Ad Absurdum  
Sundry Mourning

### Neighborhood Websites

<http://www.birthandbeyond.com/classes.html>  
<http://www.dailycandy.com/kids/seattle/>  
<http://www.fremontuniverse.com/>  
<http://www.magnoliavoices.com/>  
<http://www.mapleleaflife.com/>  
<http://www.myballard.com/>  
<http://www.mygreenlake.com/>  
<http://www.mywallingford.com/>  
<http://www.phinneywood.com/>  
<http://www.queenanneview.com/>  
<http://www.redtri.com/seattle>  
<http://www.udistrictdaily.com/>  
<http://www.wedgwoodview.com/>  
<http://www.westseattleblog.com/>  
<http://www.whitecenternow.com/>

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

### Other Outreach

African Americans Reach and Teach Health  
Birth and Beyond (baby store)  
Center for Human Services in Shoreline  
Community of Mindful Parents (service provider)  
Department of Health news release, Facebook and twitter posts, newsletter  
El Centro de la Raza – Hilda Magana  
Foundation for Early Learning Newsletter  
Group Health Foundation  
King County – blast fax to VFC providers  
King County Department of Health – Jeff Duchin  
King County Medical Society  
La Leche League (State of Washington and Seattle)  
Mohamed Ali, MPH, from Hope Academic Enrichment Center  
Mommy Matters organization (website)  
Moms Clubs (private organizations)  
My PEPS Group Forum  
Public Health–Seattle and King County (PHSKC) - list of participants from public engagement meetings, listserv of emergency preparedness public educators  
School Nurses  
Seattle’s Child organization  
Seattle MamaDoc blog post and tweet  
Shoreline Conference Center website  
Washington County Academy of Family Physicians  
Wellspring Family Services – Vicki Burr Chellin  
WithinReach Facebook posts

### Others Receiving Information from Local Hosts

ACIP and NVAC members and and ex-members in Washington – Jeff Duchin, Ed Marcuse, Kathleen Neuzil, Janet England, Jon Almquist, Bill Foegen  
Child care centers  
Health plan immunization quality improvement staff  
Health plan representatives  
Immunization coalitions  
Keystone Center – participants in other public engagements  
Legislators and legislative staff  
Local health representatives (both local health immunization coordinators and local health leadership)  
Medical Association representatives

- Family practice (WAFP)
- Naturopathic medicine (Bastyr)
- Nurse (WSNA)

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

- OB/GYN
- Pediatric nurse practitioners (NAPNAP, ARNPs United)
- Pediatricians (WCAAP)
- Pharmacy association (WSPA)
- Washington State Medical Association

Public health leaders – State Health Officer, Secretary of Health, State Epidemiologist

School nurses and school support staff

State agency partners – Health Care Authority, Department of Early Learning, Office of the Superintendent of Public Instruction

Washington State Board of Health

Washington Vaccine Association

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## CHICAGO RECRUITMENT ACTIVITIES

In Chicago, the local hosts from the Illinois Department of Public Health, Chicago Department of Public Health, and the Chicago Area Immunization Campaign conducted the recruitment effort. The team developed a strategy to recruit in waves, starting with the entities and individuals with the closest relationship with the public health departments, followed by a staff-organized outreach effort to recruit parents and entities that serve parents (a potential pool of 2,500 people). The first wave of outreach went to 180 invitees, a second wave to 400 members of the Chicago Area Immunization Campaign, and others from a mailing list of 2,500. Contacts included the following:

### Representatives of County and City Health Departments

Champaign-Urbana

Cook County – Christina Welter

DuPage County – Rashmi Chugh

Evanston

Jackson County – Miriam Link Millison

Kankakee

Lake County – Karyn Lyons, Roni Weiss

Livingston County

McHenry County

Oak Park

Peoria

Skokie

Springfield

Stickney

Will County

Winnebago County

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

### Other State/City Departments/Boards

Chicago Public Schools  
Head Start  
Illinois Department of Child and Family Services  
Illinois Department of Healthcare and Family Services  
Illinois Department of Human Services  
Illinois State Board of Education  
Illinois State Board of Health  
WIC Offices

### Doctors

Ken Alexander –University of Chicago  
Rachel Claskey –University of Illinois  
James Conway –University of Wisconsin  
Robert Daum – University of Chicago  
Kathy Swafford – Southern Illinois University  
Tina Tan – Northwestern University  
Dennis Vickers – Sinai Children’s Hospital

### Universities

Loyola Medical School  
Northwestern School of Medicine  
Southern Illinois School of Medicine  
University of Illinois College of Nursing  
University of Illinois School of Public Health

### Professional Organizations

American Academy of Pediatrics –Elizabeth Sobczyk  
American Congress of Obstetricians and Gynecologists  
American Medical Association –Sarah Duggon Goldstein  
Illinois Association of Family Physicians  
Illinois Association of Nurses  
Illinois Chapter of the American Academy of Pediatrics  
Illinois School Nurses Association  
Illinois State Medical Society  
National Medical Association  
Nurse Midwives of Chicago  
The Student National Medical Association at the University of Illinois

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

### Other Public Health Organizations

Illinois Primary Health Care Association  
Illinois Public Health Administrators Association – Toni Corrona  
Illinois Public Health Association – Jim Nelson  
Northern Illinois Public Health Consortium  
Metropolitan Chicago Healthcare Council  
Public Health Institute of Metropolitan Chicago – Patrick Lenihan

### State Legislators

Pam Althoff  
Sarah Feigenholtz  
Robyn Gabel  
David Harris

### Insurance Companies

Aetna  
Blue Cross Blue Shield – Amy Parry  
Humana – Mary Gallagher  
Insurance Association – Dierdre Manna  
United Health Care

### Citizens Groups

Junior League  
Kiwanis Club  
PTOs/PTAs  
Rotary International

### Daycare Providers

Illinois Action for Children  
Providers – geographically diverse

### Religious

Churches, synagogues, mosques  
Community Renewal Society

### Media

Julie Deardorff – *Chicago Tribune*  
Liz Hoffman – *Chicago Parent*  
Trine Tsouderos – *Chicago Tribune*

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

### Other Disease Organizations

Developmental Disabilities group  
Mainstream Autism Group  
National Kidney Foundation  
Respiratory Health Association – Joel Affrick, Doreen Minnice

### Minority Health Groups

Asian Health Coalition – Ginny Heller  
Chicago Hispanic Health Coalition  
Chinese Mutual Aid Society  
Illinois African American Coalition for Prevention  
Korean Community Services  
Mujeres Latinas En Accion  
National Medical Association

### Pharmacists

Pharmacy Association  
University of Illinois Pharmacy School  
Walgreens, CVS, Jewel-Osco, Dominick's

### Hospitals

Children's Memorial  
Comers  
Downstate  
Jackson Park  
Loyola  
Lutheran General  
Northwest Community  
North Shore University  
Rush Peds  
Sinai Children's Hospital  
Springfield

### Youth

Pregnant Teens from Campaign to Save Our Babies  
Youth Advisory Committee for Illinois Coalition of School Health Centers

### Other

Catholic Charities

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

HealthConnect1 – Rachel Abrams  
Illinois Foundation for Quality Healthcare  
Infant Welfare Society  
Infectious disease doctors  
Jewish Federation  
Jonathan Goldman – Education/parents PAC  
Kenzie Cameron – Medical Communications, Northwestern University School of Medicine  
Lutheran Child and family Services  
March of Dimes  
Metropolitan Family Services  
Oz of Prevention – Nancy Sheir  
Private family physicians  
Private OB/GYN providers  
Private pediatricians  
United Way of Chicago  
Voices for Illinois Children  
YMCA  
YWCA

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## DENVER RECRUITMENT ACTIVITIES

In Denver, the local hosts from the Colorado Department of Health and Environment, Colorado Immunization Section, and the Colorado Children's Immunization Coalition were helpful in sending the meeting invitation to their large listservs. The Keystone Center reached out through phone and email to more than 150 other individuals and community groups within the Denver area. Following is an extended list of many of the contacts:

### Children and Education Groups

Auraria Early Learning Center  
Colorado AfterSchool Network  
Colorado Bright Beginnings  
Denver's Great Kids Head Start, Mayor's Office for Education and Children  
Denver Children's Home  
Denver Early Childhood Council  
Denver KinderCare  
Elementary Schools across the region (private and public)  
Hope Center  
Little Friends Learning Center  
Montessori School of Denver

# Appendix D—Recruitment Activities

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## Recruitment Contacts and Activities by Location

Padres Unidos  
Primrose School at Stapleton

### **Community and Civic Organizations**

Asian Pacific Development Center  
Bridges Family Services  
Christian Community Services  
Denver Housing  
Denver Rescue Mission  
Irish Fellowship Club  
Libraries throughout the Denver Metro Area  
League of Women Voters of Denver  
Metro Volunteers  
Metro Denver Partners  
Muslim Family Services of Colorado  
Mi Casa Resource Center  
Mile High United Way  
Salvation Army  
YMCA throughout Colorado

### **Public Health and Medical Groups**

Center for African American Health  
Colorado Academy of Family Physicians  
Colorado Association for School-Based Health Care  
Colorado Coalition for the Medically Underserved  
Colorado Community Health Network  
Colorado Foundation for Medical Care  
Colorado Health Institute  
Colorado Wellness Foundation LLC  
Clinica Tepeyac  
Kaiser Permanente  
Local health departments statewide  
Denver Red Cross  
Penrose St Francis Hospital  
Private providers

### **Neighborhood and Parent Groups**

Aurora Interfaith Task Force  
Colfax Community Network  
Highland Mommies  
La Leche Leagues throughout the Front Range area

# Appendix D—Recruitment Activities

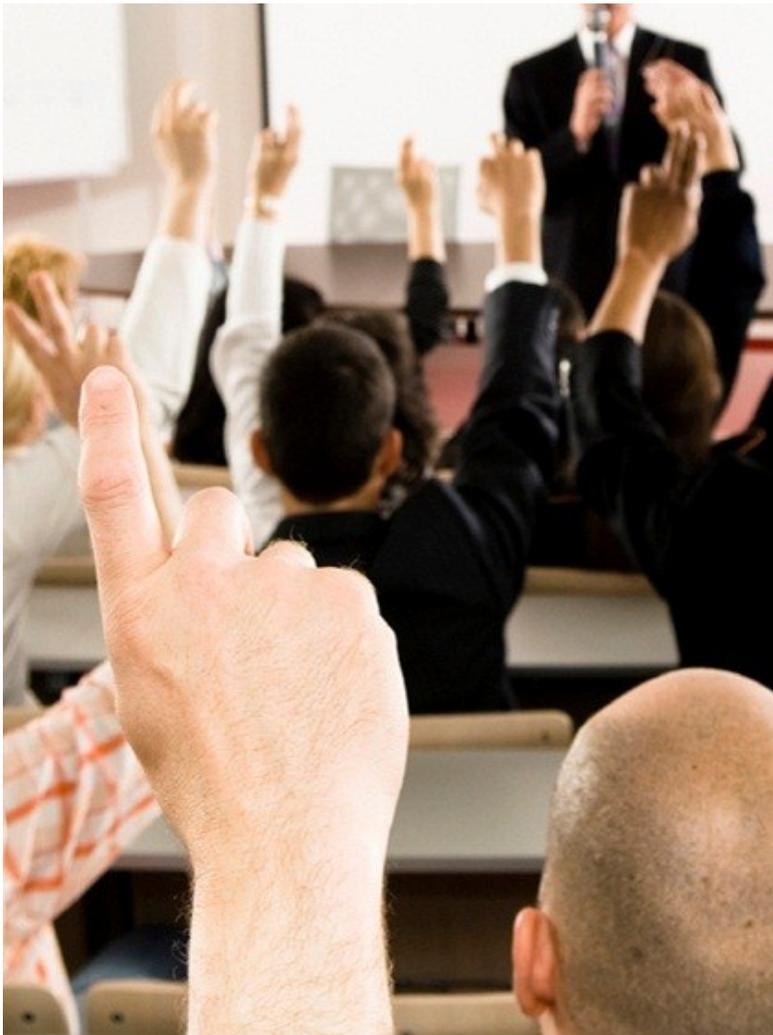
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## **Recruitment Contacts and Activities by Location**

Mile High Moms  
Moms Club of Wash Park  
Moms Like Me Denver  
Mothers of Preschoolers (MOPS) groups across the state  
Newcomers Club  
Stapleton Healthy Moms  
Stapleton Moms  
Tennyson Center for Children and Families  
University Park Moms  
West Washington Park Neighborhood Association

### **Other Groups and Organizations**

Colorado Children’s Campaign  
Family Voices of Colorado  
National Conference of State Legislators  
Women in Government



**Headquarters**

1628 Sts. John Road  
Keystone, CO 80435  
Phone: 970-513-5800  
Fax: 970-262-0152  
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**Denver Office**

1600 Broadway  
Suite 1920  
Denver, CO 80202  
Phone: 303-468-8860  
Fax: 303-468-8866

**Washington, DC Office**

1730 Rhode Island Avenue, NW  
Suite 509  
Washington, DC 20036  
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Fax: 202-452-1138

