# Summary

## Workshop on Vaccine Communication
## October 5-6, 2000
## Key Bridge Marriott Hotel, Arlington, Virginia

The purpose of the workshop was to provide a forum for identifying and discussing more effective approaches to vaccine benefit and risk communication. The National Vaccine Advisory Committee, the Department of Health and Human Services' Inter-Agency Vaccine Communications Group, and the National Vaccine Program Office sponsored this workshop. The objectives of the meeting were to:

1. Identify key issues, forces, and trends that are influencing and shaping perceptions about vaccines.
2. Determine how to establish meaningful discussions regarding issues of concern.
3. Define options for establishing more effective approaches for communicating vaccine benefits and risks.
4. Examine and discuss the effectiveness, purpose, methods, and timing of current vaccine communication.

**Workshop Structure**

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| Thursday, October 5 | 8:30am – 6:00pm | Plenary Presentations and Panel Discussions |
| Friday, October 6 | 8:30am – 11:45pm | Breakout Sessions |
| | 12:00noon – 1:30pm | Breakout Session Reports/Wrap-up & Next Steps |

Interest in the Workshop was intense, as borne out by attendance and participation. More than 175 persons took part in the 2-day meeting, representing a broad cross-section of constituencies, including:

- Vaccine and public health communications and public affairs specialists
- Vaccine consumer and parent organizations
- Vaccine manufacturers
- Health policy and benefit-risk researchers
- Health educators
- Health care providers
- Managed care organizations
- State and local immunization program directors and managers
- Health and medical reporters

### Session 1: Vaccine Communication: Purpose, Effectiveness, and Needs

***Moderator: Michael Decker***

**What makes vaccine risk communication unique?** **Speaker: Geoffrey Evans**

- Traditionally, health risk communication has consisted of one-way messages aimed at reducing individual or societal risks like smoking and seat belt use.
- The field of health risk communication, including the science and practice of vaccine risk communication, is in its infancy but this is changing. In 1996, the Institute on Medicine (IOM) held a workshop on vaccine risk communication, which was a good first start in understanding this discipline. Several articles also came out of that workshop.
- Environmental and Health Risk communications is increasingly becoming an interactive process with an

exchange of information and opinions.

- The concept of risk communication was highlighted in the 1989 National Research Council Report entitled "Improving Risk Communication," which emphasized that the goal of any risk communication process should be better public understanding and better-informed individuals and societal choices. A key point is that the process is viewed as successful only to the extent it first improves or increases the base of accurate information decision-makers use, be they government officials, industry, managers, or individual citizens; and second, satisfies those involved that they are adequately informed within the limits of available knowledge.
- Vaccine risk communication is all about the interaction between health care providers and parents to ensure that parents are adequately informed. This is facilitated by the use of CDC-published materials mandated under the National Childhood Vaccine Injury Act of 1986. By law, all health care providers giving vaccines covered by the National Vaccine Injury Compensation Program must provide a current Vaccine Information Statement (VIS) to patients or, in the case of minors, their parents or legal representatives. Each VIS is written on the fifth- to seventh-grade level and details the benefits and risks of the vaccine along with information about the Vaccine Adverse Event Reporting System (VAERS) and the injury compensation program.
- The benefit side of vaccines is less evident for the consumer while information on vaccine adverse events is widely publicized and more available through the media and the Internet, often with conflicting information.
- Common misconceptions about vaccines are:
    - Vaccines have done little for diminishing disease rates that we have seen.
    - Vaccines are 100% effective.
    - Vaccines cause immune system overload.
- The office or clinic is the frontline of immunization, a place where we have much to learn about what is being done and not being done to communicate benefits and risks.

**Vaccine communication: Current needs and approaches** **Speaker: Glen Nowak**

- The goal of vaccine communication is to create relevant, understandable, and credible messages; and to produce and disseminate responsive, helpful materials that are visible, accessible, and well organized.
- Two important perspectives guide the Centers for Disease Control and Prevention's (CDC) National Immunization Program's approach to vaccine communication: 1) the individual's perspective, which includes the parent perspective; and 2) the community or society perspective. There are typically six questions used to formulate communication strategies, develop tactics, and respond to questions and concerns. These are:
    - Who is our audience?
    - What are we trying to achieve?
    - What factors are important or most important for helping us achieve that goal?
    - What messages and materials do we need to develop?
    - How should we disseminate those materials and messages?
    - Who are the credible spokespeople?
- Vaccine communication has challenges. The challenges are:
    - The diverse populations and audiences. Different subpopulations or audiences have different information needs, whether you're talking about parents, health care professionals, or the public. One message does not fit all.
    - The media goals and motives which differ from ours.
    - The complexity of communicating the three most important things: the schedule, the science, and the safety. These three are complex and are becoming more complex.
    - Science that is a dynamic, evolving enterprise. What might have been true today might not be true tomorrow.

- Vaccine communication has needs. The needs are:
    - Greater understanding of parents' and patients' interests and concerns.

- A broader portfolio of materials and resources.
- Continued improvement in how science and uncertainty is translated.

**Panel I: Physicians and other providers: What are the communication needs, and how they are being met?**
***Facilitator: Leslie Ball***

**Speakers: Virginia Burggraf, Terry Davis, Bruce Gellin, Denia Varrasso, and Richard Zimmerman**

- The results of many focus groups indicate that parents look to their children's doctors for information about recommended vaccinations. Doctors and pediatricians in particular, are the most important source of information. Interpersonal communication and written materials are important and that speaks to the need for development of the right kind of materials for the audience. This should not, however, take away from the discussions that parents expect and want to have with health care providers.
- A national study (27-item survey mailed to a random national sample of pediatricians and family physicians and their office nurses), by Louisiana State University Health Sciences Center-Shreveport, found a gap between legal mandate, the American Academy of Pediatrics' guidelines, and the actual practice of vaccine communication. Providers in over a third of the pediatric and family practice settings reported that they were not giving the VISs or verbal vaccine risk and benefit communication. The study also indicated that about 70 percent of providers self-reported that they are telling parents about side effects, how to treat the side effects, when to call the clinic, and the schedule for the next vaccine**. Note: The results of this study, "Childhood Vaccine Risk/Benefit Communication in Private Practice Office Settings: A National Survey," has been published in *Pediatrics*, Vol. 107, No. 2, February 2001**.
- Results of a pilot study (presented at the American Academy of Pediatrics' Year 2000 meeting) in two large pediatric practices in Shreveport, Louisiana showed:
  - VISs were given in only one-third of the immunization visits.
  - Physicians initiated some vaccine communication about two-thirds of the time.
  - Nurses initiated vaccine communication about one-half of the time.
- In a study done by LeBaron and the Rochester group, researchers found that 79 percent of parents indicated on a questionnaire that the VISs greatly increased their understanding of vaccines yet only 5 percent were observed actually reading a VIS in the clinic. This study indicates that even if providers give VISs, verbal risk and benefit communication is important.
- Risks of highly infectious diseases that can kill and maim far outweigh remote risks from vaccine side effects.
- Pressures from managed care and sick patients limit the time available for discussions between physicians and patients about vaccine safety.

**Panel II: Parents and consumer groups: What are the communication needs, and how well are they being met?**
***Facilitator: Amy Fine***

**Speakers: Barbara Fisher, Peter Meyers, and Trish Parnell**

- There are major gaps in scientific knowledge about vaccine risks. The lack of scientific understanding is affecting the quality of vaccine benefit and risk communication.
- The foundation of benefit and risk communication is dependent upon the quality and quantity of the science used to define those benefits and risks. If the science used to license new vaccines and make vaccine policy is methodologically sound, reproducible, and openly shared with the public by industry, Federal agencies, and medical organizations, educated vaccine consumers will have fewer questions about vaccine safety and efficacy. Health care consumers are looking for more information and control over health care decisions that involve risks. Informed parents want a more equal partnership with doctors in making vaccine decisions for their children.
- If the science is inadequate or not shared openly but is kept behind closed doors or hidden away in large linked

electronic databases, then vaccine consumers, as well as doctors, legislators and journalists investigating vaccine benefits and risks will continue to raise questions.

- The call for reform of the mass vaccination system by parents has never been about telling people not to vaccinate. It has always been about better defining and communicating vaccine benefits and risks so children can be protected from both infections and vaccine complications. Also, it has always been about identifying genetic and other biological factors that place some children at higher risk than others for suffering vaccine reactions in order to spare their lives.
- With American children now routinely receiving 37 doses of 11 different vaccines in the first 5 years of life and with more than 200 new vaccines being developed, vaccine consumers are calling on industry and government to conduct the research to find out why bright, healthy, normally developing children get vaccinated, and then suddenly regress physically, mentally, and emotionally. They are left with learning disabilities, hyperactivity, autism, epilepsy, mental retardation, asthma, or diabetes.
- Once good science is done to better define genetic, environmental, and other cofactors, which make some children more vulnerable to suffering vaccine complications, public confidence and trust will not be an issue in vaccine benefit and risk communication because the vaccine policies will be tailored to the individual rather than forcing individuals to adhere to one size fits all vaccine policies.
- The quality of information available to parents and the general public is excellent. However, more simplified methods and venues for accessing the information need to be established. As well, parents must be responsible and seek information on the risks and benefits of vaccines.
- When parents need a vaccine answer specific to their child's situation, they should know to contact their child's pediatrician or family physician for information and for help in deciding what is best for the child. The parent and the pediatrician must jointly make medical decisions for the child.
- There remains a lot to be done in terms of how to communicate different perspectives, and how to communicate from a consumer perspective. The benefits and risks of vaccines as well as the risks of not vaccinating must be communicated in a manner that is not only understandable to informed parents but also comprehendible to parents who may be less informed.

**Session 2: Effective Approaches for Communicating Benefits and Risks**
***Moderator: Adele Young***

**A mental models approach to vaccine risk communication** **Speaker: Ann Bostrom**

- Vaccine risk communication has several common problems. There is a lot of uncertainty about risks and benefits of vaccines, and this stems from several sources, including a lack of data, disagreement about the interpretation of existing data, and a lack of biologically plausible theories to explain health effects that some attribute to vaccination.
- To be effective, risk communication has to convey what the hazard is, what the risk is, and how to reduce it – the risk must be perceived as severe and personally relevant, a threat to the person, and controllable.
- A mental model is a person's prior belief or idea about an issue or subject matter. The belief is reflected in the person's way of thinking.
- People already have a mental model of some disease and vaccine risks. They have reference or ideas about what the causal chain is and this includes beliefs about how these risks can and cannot be controlled. To be effective, communication has to address these prior beliefs.
- There is research showing that if you do not address people's existing causal models, they will adapt the information that they hear to what they already believe. People's thinking cannot be changed about risks or hazardous processes without looking at their prior beliefs.

- The four-step approach to risk communication based on people's mental models of risk processes are:
  - Open-ended elicitation of people's beliefs about a hazard, allowing expression of both accurate and

inaccurate concepts.
    - Structured questionnaires designed to determine the prevalence of beliefs.
    - Developed communications based on those elicitations as well as on decision-analytic assessment of what people need to know in order to make informed decisions, along with the psychological assessment of their current beliefs.

    - Interactive testing of communications using open-ended, closed-form, and problem-solving instruments administered before, during, and after the receipt of messages.
- Experts' mental model approaches to problem solving differ from that of lay people; therefore, public participation will enable more effective risk communication.
- Communication should make recipients' mental model more complete, more accurate, and specific enough for the decision-making they face about the risk. This is done by covering the basic facts from the expert model, addressing any major misconceptions, and filling any gaps that might exist between the two.
- It is clear from a lot of research on probabilities that the interpretation of verbal probability "rarely" or "likely" depends on the context. It is also clear that people who are non-experienced in dealing with probabilities of risk do not appear to accumulate estimates of single exposure at a high enough rate, so it might be preferable to communicate cumulative risk; in other words, risk over a lifetime as opposed to a single exposure over a single year.
- Risk communication must be flexible so that people have a choice of how much information they get – tiered information that is simple, to the point, and brief to information that allows people to look at the alternatives, assumptions, and degree of consensus with regard to uncertainties, and where they can go for more information.

**Risk perceptions and decision-making** **Speaker: Jonathan Baron**

- People's decisions on vaccine issues can be understood in terms of the "heuristics-and-biases" approach to the psychology of judgments and decisions.
- A normative model in this field means an idealized standard for how we evaluate people's judgments and decisions. The normative model relevant to the study of vaccines is the expected utility theory.
- Expected utility theory treats a decision as if it were a gamble, multiplying the probability of each outcome by its value to you. Instead of converting it to money, our measure of value is "utility." So in the case of vaccine the utility of getting the vaccine (as opposed to not getting it) is the sum of two parts. The first is the probability of avoiding a disease (which you would otherwise get) times the utility of that outcome, and the second is the probability of a side effect from the vaccine times its utility. This can be complicated by considering more than one side effect and the monetary cost. Another point about this model is if each person makes a decision according to this model, the total utility over a large group of people is maximized. So expected utility theory for individuals amounts to utilitarianism for populations. That is the idea of maximizing total utility.
- The interesting thing about vaccines is that in contrast to many other areas of public life, the establishment in the vaccine world generally supports the expected utility model. This is the way people, the experts, tend to think about vaccination, at least to a first approximation. If we use this as a normative model - an idealized standard that defines, in essence, the right answer - then people systematically depart from this model. They do this because they use heuristics. Heuristics are short-cut methods of thinking that are good most of the time, but lead to trouble some of the time.
- One heuristic is "do no harm." It refers to action but not to inaction. People tend to ignore the harm that results from doing nothing, when an alternative is available. This leads to "omission bias," a bias toward harm caused by omissions, as opposed to acts.

- The following psychology experiment is an example of omission bias. Subjects were told: "A kind of flu can be fatal to children under three. A vaccine has been developed and extensively tested. The vaccine prevents the flu but it can sometimes cause side effects that can be fatal. The death rate for unvaccinated children is 10 out of 10,000. The death rate for vaccinated children is 5 out of 10,000. These children die from the vaccine that

totally prevents the flu." According to expected utility theory, you should vaccinate and, in fact, you should vaccinate if the death rate from the vaccine was 9 out of 10,000 because the chance of death is still lower. Some people will go all the way up to ten. Other people will not vaccinate if the risk is one. They will not take any risk of death from the vaccine in order to prevent a fairly substantial risk of death from the disease. People worry more about harms of action rather than harms of omission, and it has nothing to do with experts versus non-experts.

- In a study done by Meszaros and Ashe, parents who had not vaccinated their children with the Diphtheria, Tetanus, and Pertussis (DTP) vaccine showed more omission bias in the hypothetical test; they were more concerned about harms of action than harms of omission, and the bias was stronger in them than in the vaccinators.
- The other types of bias are bias toward nature and bias toward differences vs. proportions. In the latter case, people like to reduce risks when they can reduce a large proportion of a small risk rather than reducing a small proportion of a large risk even though the latter is more reduction.
- People need numbers to make good decisions about risk. If they are going to follow expected utility theory, then they have to have the best numbers available. But even with the numbers, people have intuitions often arising from strongly held moral views, and tend to focus on the numbers that support what they already believe (i.e. the numbers strengthen their belief no matter what it was – the polarization effect). When people act according to their intuitions, they actually get what they want. That is, outcomes that are less than the best possible outcomes.

**Communicating complex and scientific data** **Speaker: Tim Tinker**

- Often the best information on vaccines does not result in the public's understanding of the information or the use of that information. There are high levels of scientific uncertainty and lack of trust. There is the issue of perceived truth. There are often things lost in the translation and this creates a very complex web in terms of not only communicating but also helping people understand scientific information.
- Situational variables, personal variables, and communication variables have a very profound influence on how people not only access but how they process information and ultimately, how they will decide to either accept or reject that information. Social influence theory would also support this thesis. Social influence is about change, and very few people make decisions in a vacuum. There are forces that are exerted or brought to bear on how people make decisions. Social influence is employed by an agent; the agent's message is called advocacy.
- There are always two sides to any communication story. On the one side, there is proponent communication. In proponent communication, the agent is "us," meaning all the individuals and the organizations that are advocating and carrying forward a pro-vaccine message with the purpose of acting upon the target audience, be it parents, the general public, health care professionals, and the like.
- On the other side there is opponent communication. In opponent communication, the agent is "they," meaning the individuals, organizations, and institutions that carry forward and advocate anti-vaccine messages.
- There are some liabilities and serious communication challenges in communicating scientific information that have to be acknowledged and worked through, such as:
    - What are some of the basic tools that a person needs in order to grasp, as well as interpret scientific information?
    - How about the individuals themselves?
    - What is the desired profile?
    - What is the desired skill set?
    - What is the person's desired level to pursue this information?

- Communication models:
    - Sense making model – this approach asks the question, "how do people make sense of information based on the nature and the use of that information?" Key assumptions: 1) discontinuity and ambiguity are constants in our life in terms of gaps in knowledge, gaps in information which can lead to gaps in

decision-making; and 2) as communicators we are not merely in the business of transmitting facts, but if we want to be able to not only understand but to close the gaps that people may experience, we have to understand that there is a role for the construction of our communication. We have to have a better understanding of the use of information and information systems that begins from the perspective of the received and not necessarily the perspective of the sender.

- Transmission model - in this model we are asking the questions that are really not from our world. How much information was sent out? Do we think the information was accurate? Do they need more information? The thought is to throw more information at the communications problem.
- Construction Model – here, our thinking and perspective shifts. What strategy did the person apply that led him or her to accept or reject the information as accurate? How should systems be designed to allow people to apply the criteria they want to their information desires and abilities?

**Panel III: Media perspective: To what extent should the media consider public safety in their coverage of vaccine issues?**

***Facilitator: Barbara Reynolds***

**Speakers: Sunny Kaplan and Bill Snyder**

- There is a love-hate relationship between the media and public health officials. Many public health officials feel that almost any reporting on the issue of vaccine safety can be negative and scare parents into not vaccinating their children.
- A reporter's job is not to promote or oppose vaccination. Reporters go to great lengths to report the truth, to report what is out there, and what they think the readers can understand based on the science that is presented. Regular news stories have to be newsworthy and timely; they have to cross a threshold, be accurate, brief, have credible sources, be compelling, and be balanced.
- The news reporting process normally has to be done in a short length of time; reporters do not have months or weeks to report a story. Basically, a reporter has hours to write a story.
- The ability of reporters to get accurate information can sometimes be a difficult task. Getting information from people who are working in the field of vaccine is a task within itself because most public health officials are very defensive toward reporters.
- In order to improve the relationship between the media and public health officials, there needs to be an established dialogue between the two parties. The public health officials should be available and ready to assist reporters with information on vaccine-related issues. There needs to be an even exchange of information. Reporters will go where they can get access to information, and if public health officials do not allow access because of mistrust of the media, then everyone will suffer from the inaccuracies.

**Session 3: Risk Communication Lessons Learned in Other Fields**

***Moderator: Max Lum***

**Panel IV: Lessons learned from the field of risk communication**

***Facilitator: Max Lum***

Myths about risk communication:

- We do not have enough time and resources to have a risk communication program.
- Activist groups are responsible for stirring up trouble.
- If we get involved with the public, we will take scarce resources away from research and good public health practice.
- The public is never satisfied.
- Talking to the public about risk is not my job.

- These issues are way too complex and too difficult for the public to understand.
- If people know the true risks, they would accept them.
- Telling the public about risk is more likely to unduly alarm people than just keeping quiet.
- Science speaks for itself.

**Speakers: Scott Ratzan, Ken Rabin, Lee Anne Jackson, and David Ropeik**

- Lessons learned from other fields:
  - Bovine Spongiform Encephalopathy (BSE)
    - Being prepared is the key in risk communication regardless of the issue.
    - Communication messages should be clear and be provided by persons that the target population(s) trusts such as doctors and teachers. (Government scientists, business leaders, and politicians -- generally government administrators and journalists -- are the ones people think do not tell the truth). There is a disconnect among whom people trust, who delivers the message, about the context of the message, and what is stated as well as what it the message means.
    - Because of ethical issues and the need to provide factual and consistent messages, strong partnerships are suggested between the public and private pharmaceutical manufacturers and stakeholders, consumers, government agencies, international organizations, etc.
  - Media
    - The media tends to play up the dramatic, negative, or controversial aspects of stories, whether it is about vaccines, crime, or politics. This is because bosses want to sell papers, and managers are looking at the bottom line and making decisions in direct pursuit of profit.
    - The personal motivation for most regular journalists, from reporters to photographers to headline writers, is not to make money. It is not to sell papers or entertain. The reporter, journalist, photographer, and headline writer are interested in getting their names and work recognized and educating the public.
    - Public health officials should be the first source the media consults. The responsibility of public health care officials is to understand the tight deadlines, be warm but business-like, be candid about what they do and do not know, and have reliable data available.
    - Reporters should be informed in advance of the problem, have access to pertinent information, and be able to quickly speak with subject matter experts. They should know who the key players are in advance of a problem. If not, they will listen to someone else and assume that the individual who is coming in with a story has the edge on the information. If you believe in what you are doing, be supportive and get the message out to the public in advance of a crisis.
  - Johnson & Johnson's Response to the Tylenol Contamination Incident
    - Johnson & Johnson acted quickly in response to the crisis. They developed a better product or a better way to use the product and reached out to constituents to educate them on the safe use of the product.
  - Food Safety Initiative
    - In 1997, the President announced a Food Safety Initiative with the intent of reducing the incidence of food borne illness to the extent possible. The goal of the risk communication was and continues to be to provide open access to food safety information and to ensure that people throughout the chain from farm to table follow safe food handling practices.
    - Initially, the challenge was educating millions of people with limited resources – partnership was critical. Partnerships were formed with industry and consumer and government organizations. They developed the key message, "Clean, Separate, Cook, and Chill" which was transmitted through the use of a puppet, communication action kits, videos, secondary school curriculum, catchy music and songs, stories, brochures in multiple languages, magazines, TV shows, and TV

and print PSAs, grocery stores, school-based education programs, and media outreach campaigns.

**Breakout Sessions**

**Overview:**

The task of each breakout session was to identify and discuss the challenges, concerns, and issues facing vaccine communication. The goal of each breakout session was to obtain diversity in opinions and ideas, in order to generate thought-provoking discussions and provide guidelines for moving forward in the area of vaccine communication. The groups were divided into three focus areas: routine communication, urgent communication, and response to uncertainty. Facilitators from Burson-Marsteller divided each of these large groups into smaller teams that addressed a number of questions, reacted to a case study, and made suggestions concerning what could be done to foster more effective vaccine communications in each of the settings.

The stated objectives of this workshop were to:

- Identify key issues, forces and trends that are influencing and shaping perceptions about vaccines.
- Determine how to establish meaningful discussions regarding issues of concern.
- Define options for establishing more effective approaches for communicating vaccine benefits and risks.
- Examine and discuss the effectiveness, purpose, methods and timing of current vaccine communications.

A detailed review of ideas and suggestions from each of the three groups will be found in the second section of this report. In brief, their ideas are summarized under three general topic headings that cut across all vaccine communications, whether they are routine, urgent, or uncertain:

**1. Transparency**

- Short, simple, multicultural communications that explain benefit and risk clearly will continue to be the mainstay of vaccine communications, but more and more consumers are demanding and can comprehend more complex scientific information.

- All the communications in the world will not matter if the audiences or stakeholders do not believe they are getting fair balance in the information they need to make an appropriate health decision.

- Focus groups and other communications research techniques used to evaluate vaccine message content and effectiveness should also examine the credibility of the message source and the presence of fair balance in the message content.

**2. Timeliness**

- Timeliness is essential in the setting of urgent vaccine communications, such as an impending outbreak of vaccine preventable illness, or recall of a vaccine due to adverse events.

- However, timeliness is equally essential in controlling rumor and fear in the uncertain communications setting, and in getting routine immunization messages to stakeholders so that they can be acted on in a timely way, such as the opening of school or the beginning of flu season.

- ❖ Timeliness is not just essential in reaching consumers or end users. It is critical in communications between and among state immunization programs, FDA, health care provider groups, and the vaccine companies. Existing regulations may impede timely communications in this regard, so too may organizational clearance procedures and protocol.

**3. Systemization**

- ❖ Workshop participants who drew diagrams describing the flow of communications between and among vaccine constituencies were struck by the relative intensity of message flow among federal, state and local immunization officials, selected medical professionals and vaccine manufacturers.

- ❖ Participants were struck equally by the relative shortage of direct information sources to consumers, who rely exclusively on the news media (which is sporadic and sensational) and medical professionals (some of whom cannot at this time be counted on to provide basic vaccine information that is available to them). Internet information sources are becoming increasingly important, but vary in quality, timeliness and bias.

- ❖ Even the most urgent and uncertain of vaccine communications are predictable to the degree that there is always a risk of adverse events, and new scientific data that conflicts with existing scientific knowledge will inevitably be generated. Vaccine communicators must be trained and prepared to manage communications in these instances, and not to be taken by surprise when the inevitable crisis occurs.

- ❖ Since the United States will need to administer national immunization policies and programs within a decentralized healthcare system for the foreseeable future, it will become increasingly necessary for those responsible for vaccine communications to carefully examine, reinforce and evaluate existing networks for message development and information dissemination.

**In Depth Reports from Break-Out Sessions**

Participants in each of the three breakout sessions were asked initially to describe what they felt were the key issues affecting vaccine communications. They then discussed what they felt were the obstacles and opportunities to establishing appropriate discussion and dialogue on these issues, as well as what would be the most effective communications mechanisms they could envision in each setting.

To further focus participant thinking, discussion and suggestions, each group also was asked to assess communications problems and opportunities in regard to a specific case study. The three cases were as follow:

1. *Routine Case Study*

   A new vaccine, administered to older children, will be approved and coming to market in the next six months. It will treat an illness that is serious for most children, and life threatening for a small but significant group.

2. *Urgent Case Study*

   A vaccine that has been on the market for several years is causing an adverse reaction among a small, but significant group of those who have received the vaccine. The reporting from doctors in practice about these adverse events leaves no argument among officials that the problem is directly related to the vaccine. While not life threatening, the adverse event does have a significant impact on the health of those most affected.

*3. Uncertain Case Study*

A new study, published by university researchers, has questioned the safety of a vaccine. The allegations are serious, the researchers are respected, but other well-designed similar studies haven't come up with the same conclusion. Other researchers are skeptical about the findings. What everyone does agree on, however, is that no one has all the facts or the final answer at this time.

Each group was then asked to answer four specific sets of questions relative to their case study:

- Who are the "stakeholders" in this situation, i.e., those who have something "at stake" in the situation? What stakeholders have the opportunity to communicate directly with each other?
- For each stakeholder group, what are the key issues that must be resolved before communication can take place – from the stakeholders' point of view?
- How can we facilitate meaningful discussion among the stakeholders to implement listening and build trust among the various groups? What process can we put in place to accomplish this?
- Brainstorm some specific communications ideas to most effectively communicate with each stakeholder audience. Think about channels of communication, tools and messengers.

The remainder of this report consists of specific comments, ideas and suggestions that were reported out from each of the three groups, by type of vaccine communications:

***ROUTINE VACCINE COMMUNICATIONS SUGGESTIONS***

- "Ideal" communications of this type must be:
  - Targeted to each audience
  - Two-way not one-way
  - Respectful, not condescending, intimidating or hostile
  - Accessible, available
  - Purposive, with a goal, such as affecting attitudes, knowledge or behavior
  - Measurable, with measurement criteria built-in to the communications process
  - Memorable, appealing
  - Culturally sensitive and relevant
  - Unbiased, giving both sides of the story

- Challenges to effective routine vaccine communications are:
  - Perception that immunization is prevalent, successful, "no problem"
  - Lack of incentive, clear guidance on how to engage in "risk-benefit" discussion
  - Cost barriers to sophisticated consumer communications campaigns
  - Need to address non-acute reactions
  - Different perception, prioritization of immunization among pediatricians versus other doctors
  - No continuity of care for many children
  - Adult vaccines not on provider or media "radar screen" to the degree that childhood vaccines are
  - Materials for consumers not accessible, with not enough information, and not delivered at the right time – the "educable moment" in hospital or during pregnancy for a new mother, for example
  - Too much one-way communications
  - Same message given to all consumer audiences, regardless of diversity
  - Poor monitoring, reporting of adverse reactions

Specific stakeholder group issues and challenges (note that workshop participants were asked to concentrate on five key audiences rather than all possible audiences):

- **Providers** often unprepared to communicate with patients, paternalistic, constrained by time and lack of reimbursement, uncertain of policies and unaware or uncertain about current vaccine policies and research.

- **Parents** not sure what sources or what materials to trust, or what relevance a statistical benefit or risk has to "my child."

- **Managed care** unsure of benefits, risk and efficacy in terms of their costs of covered lives, unaware of which immunizations are mandated versus those that are recommended.

- **Policy makers** not equipped to judge quality of science in conflicting studies, unable to separate social from individual costs of mandatory immunization, unsure of the credibility and potential conflicts of interest of vaccine policy boards.

- **Media** not always sure that routine immunization communications are newsworthy, nor sure of best sources of information, current data, accurate information on benefits and risks.

❖ Some potential solutions in routine vaccine communications:
- Seek reimbursement of medical professionals for providing vaccine information and education to consumers (similar to cognitive services in pharmacy).
- Get best available vaccine information and vaccine communications skills content into medical and nursing school curricula.
- Train other staff in physician offices to provide immunization information.
- Reach patients and consumers at all points of contact.
- Build partnerships and alliances with third parties outside of the health care arena to transmit immunization information (churches, civic groups, school groups etc.).
- Improve the quality of immunization information materials and their distribution, understanding that more communications is not necessarily better communications.
- Recognize that "low literacy" is not the same as "less information."
- Build in routine measurement of communications effectiveness and outcomes.
- Establish and maintain ongoing media relations, including access to senior scientists who are articulate communicators.
- Encourage open, transparent dialogue and decision making between parents and physicians.
- Provide clear but comprehensive scientific information.
- Move beyond "us-them" polarization of dialogue in reference to parent groups concerned with vaccine reactions and safety.
- Embrace diversity of opinion and audiences.

***URGENT VACCINE COMMUNICATIONS SUGGESTIONS***

*Note that this summary and the one that follows do not repeat similar ideas and suggestions found in the Routine Vaccine Communications group report above.*

- Key issues in urgent vaccine communications:
  - Obtaining timely consensus among vaccine program leaders on data, messages and action recommendations in urgent situations, need for a manageable "chain of command" in what is essentially a highly decentralized system.
  - Knowing who is prepared to speak on behalf of the vaccine program, the manufacturers and providers.
  - Building media and policy maker contacts and trust in advance of urgent situations.
  - Knowing where individual consumers can go for help.
  - Understanding the value of appropriate assurances as opposed to false ones.
  - Managing confidentiality issues.

- Potential solutions or action plan steps in urgent vaccine communications:
  - Have an urgent (or "crisis") communications plan in place, at both the inter-agency and intra-agency level, test it to see if it works, evaluate the outcomes of the test and upgrade the system accordingly.
  - Identify and train spokespersons.
  - Develop strategy and technique for rapid message development and issuance of statements.
  - Know in advance all contacts in media, constituency organization and industry (phone, fax, e-mail, beeper, cell) and update list accordingly.
  - Obtain, maintain and test multiple outlets for incoming and outgoing communications – media lists, fax alerts, hot lines, e-mail list servers.
  - Be prepared to conduct live "town hall" meetings, telephone conferences with multiple constituency groups, state and local program leaders and media, as needed.

***UNCERTAIN VACCINE COMMUNICATIONS SUGGESTIONS***

- Ideal communications criteria in addition to those named above:
  - Ability to quickly verify that recipients have gotten them message, understand it and are responding appropriately to it – feedback.
  - Relevance of the message to the stakeholders' informational needs.
  - Credibility of the message source, especially when there is uncertainty or ambiguity.

- Specific barriers to uncertain communications:
  - Rumor and uncertainty, anecdote and exaggeration
  - Missed opportunities and false starts
  - Too many messages and messengers
  - Red tape
  - Lack of media and consumer pre-education to the language of immunization, public health and benefit-risk communications

- Recognize the broad range of groups who can legitimately considered as "stakeholders" in vaccine communications generally, and in the "uncertain" setting, in particular. The participants in this workshop group developed the following overall list of stakeholders:

  - Congressional (and state legislative) staff.
  - Vaccine researchers (proponents and opponents) and other medical researchers (many researchers whose medical and scientific credentials not directly related to infectious disease and immunology may be interested or ask to comment on vaccine issues).
  - Vaccine company officials and scientists
  - HMOs and other private sector health plans

- State and local health departments
- State and local medical societies
- FDA, CDC and international health organizations (national and global)
- Physicians
- Nurses
- Patients, families.
- Shareholders and investors
- Health advocacy groups
- Religious leaders
- Cultural and ethnic organizations
- Attorneys
- Internet information providers
- Traditional mass media, national and local

❖ Key stakeholder group issues:

These were delineated as follow for five key stakeholder groups from those listed above:

- **Scientists and researchers** must be clear on the methodology, data quality, investigator credibility and potential or actual regulatory consequences of a study that they may be seeing for the first time, so that they can comment accurately and promptly. This argues for a vaccine clinical research tracking system.

- **State and local health departments** require timely, clear guidance from national bodies. It must be recognized that state and local immunization officials may well get blindsided by requests for media interviews regarding a new publication of data of this type. For example, many medical journalists in important regional markets such as Boston, Miami, Chicago, Denver and San Francisco get advance copies of major medical journals before doctors do.

- **Vaccine manufacturers** face immediate regulatory confrontation (potential product or batch recall), potential litigation, shareholder and financial analyst questions.

- **Physicians** will probably see or read media stories about this study before they see the scientific article, and will require timely, straightforward guidance from vaccine program officials and/or their professional societies in order to respond to patient questions and concerns.

- **Advocacy groups** must pre-identified, and credibility established with key contacts so that there is no delay in communicating vaccine program awareness, guidance and proposed action when new data may reinforce previous fears of create potential new uncertainties.

❖ Initial communications suggestions (above and beyond those identified by the two previous groups) include:

- Be proactive, don't wait until new uncertainty is upon you to build and maintain communications links to stakeholder groups.
- Be up front about conflicts of interest, real or perceived, and explain about how they are being managed to protect the integrity of the immunization program and the vaccine communications process.
  - Don't just put out data, explain its implications and how it can be used, by media, by providers, by consumers in making appropriate immunization decisions.
  - Don't delay in responding to new, uncertain or ambiguous findings – say what you know and what you don't know, explain the steps that are being taken to clarify the situation, and give the best, most prudent advice

you can given the underlying uncertainty. Update with new information as soon as it becomes available.

- Make sure that the information being disseminated is given out in "one voice" regardless of the numbers of national, state, local, governmental, university or industry spokespersons that may need to be involved. That said, the fewer spokespersons (and the more authoritative and articulate they are), the better!
- If a public hearing is required – lay or scientific, or both – make sure it is convened and chaired by an autonomous, respected third party.