

**CHILDHOOD IMMUNIZATION STUDY
FOCUS GROUPS WITH AFRICAN AMERICANS
NEW YORK CITY
6:00 PM October 28, 1997**

Moderator: Barbara Hairston

HIB/CHICKENPOX

I. RESPONDENT PROFILE

This group was made up of ten respondents, eight (8) females and two (2) males. All were parents of young children, ranging in age from 4 weeks to 13 years.

The mothers in the group were young and several tended to equate taking care of themselves with having their hair and nails done regularly. The men in the group used physical outlets as a means of taking care of themselves, e.g., bowling and basketball.

Generally, the group tended to have limited knowledge of immunizations beyond what was mandatory for school attendance.

II. ATTITUDES AND PERCEPTIONS OF VACCINES

Objective: To gain insights into respondents' attitudes and perceptions of childhood diseases and vaccines.

Awareness of Vaccines

Respondents had limited knowledge and awareness of the vaccines that are available to prevent childhood diseases. The group generated the following list of childhood vaccines:

- Polio
- Measles, Mumps, Rubella
- Chickenpox
- Hepatitis B

Respondents tended to think of the purpose, the process and the negative aspects of immunizations when they heard the word "vaccine." The words and images associated with immunizations are listed below:

<u>Purpose</u>	<u>Process</u>	<u>Negative Aspects</u>
protection	needles	confusing
healing children	medicine	risk
prevention	doctors	side effects
safety		fever
		soreness
		cranky babies, crying

Immunizations – Required Or A Parent’s Choice

The general consensus was that immunization is a requirement to attend school. This fact virtually eliminates a parent’s choice in whether or not to immunize. It should be noted that respondents in this group believed in the purpose of immunization and probably would opt to immunize their children if it meant minimizing the chances of having a sick child.

“You have a choice, but how far do you want to take it.”

“When the doctor recommends it, you tend to go that way rather than with people from the old school.”

One respondent had recently had chickenpox as an adult. She spoke of the discomfort of the effects of the disease.

“I’d rather deal with the little side effects than the big whole picture when they don’t get the shot.”

The belief of whether or not immunization was a choice was said to be a function of timing, i.e., "old school" thinking versus that of today. In addition, respondents cited a connection between the increased risk of contracting diseases and the greater exposure of children today because they attend daycare centers earlier.

“When our parents were growing up, you had a mother home so you didn’t have to worry about them getting certain things.”

The legal implications of choice were also mentioned. Specifically, respondents believed that if children were not immunized the parent could be charged with medical neglect. School immunization requirements were also said to take immunizations for some diseases out of the realm of choice.

Respondents spoke of the Dept. of Child Welfare coming into your life or worse, having a sick child. “Then you’ll be beating yourself up for the rest of your life.”

When Others Do Not Immunize

The respondents were generally pro-immunization. Their speculations on why others do not immunize included religious reasons and culture. Some just get the main required shots that are required for their children to enroll in school. This was said to include the MMR. Hepatitis B was perceived to be new, and probably not required.

“The chickenpox shot, I think is new. That one is probably optional. Right?”

Safe or Risky

The group generally agreed that vaccines were safe. The risks which were cited were those which were described in the VIS which respondents read just prior to the discussion.

Though respondents acknowledged the risk, they generally agreed that “there are risks in everything you do.” Respondents did agree that babies should not be subjected to so many vaccines at one time. Multiple shots were also said to be frightening because of all the potential side effects.

Areas of Confusion

Respondents did not seem clear on whether immunizations reduced or eliminated the chances that a child would contract the disease for which he was immunized. Some thought that the child might still get the disease but in a less severe form.

“.....so rather than having the full blown chickenpox, or polio, or what have you, it’s still milder.”

Source of Information about Vaccines And Immunizations

Respondents agreed that they tended to receive information at the doctor’s office. However, they pointed out that it tended to be while they were there with the baby and distracted by caring for the baby.

“You know they want you to hold the baby and then they say, ‘Here you go, Tina, read this.’ They really don’t give you enough time to read, like we’re sitting here and get a chance to read and analyze it.”

Timing was a key complaint for the dissemination of information. Most suggested that the information was given after the baby was born and during office visits which did not allow enough time to read, understand and make an informed decision. Most suggested that per-natal information would have been more helpful.

Alternate Sources of Trusted Information’

The library and family members were suggested initially as trusted sources of information. None of the respondents said that they had gone to either source for information at this point, other than informal conversations with family members.

“You listen to your family members a lot, especially your mother.”

The concern with relying on information from family members was that it was not always reliable and was sometimes a source of misinformation. This was primarily attributable to the changing times and new developments in medicine that were not available to older family members.

A web site as a source of information generated mixed reactions. Most of the respondents said that they would not use a web site, citing that it would take too much time. Instead, they said they would call the doctor. Most respondents wanted to be face to face with a doctor. Information to be communicated was said to be too personal. However, if there was an interactive area that allowed a conversation, that would be preferable to leaving information and being contacted later by e-mail. Also the source of information, i.e., doctor or other health professional would have to be identified. Not knowing the source of information was cause for concern.

Preferred Form and Timing of Information

Respondents tended to agree that during pregnancy was the better time to be informed about immunizations needed for the child when born. One respondent believed that babies were frequently immunized even before the baby was brought to the mother in the hospital. This was an issue because the baby was immunized without the mother being informed or knowledgeable about the vaccine.

“While you’re in the hospital, before you even get your baby sometimes, they’ve already given your baby a shot.”

Others agreed that this procedure occurred. There was disagreement on whether the mother was informed prior to the immunization occurring.

I. REACTIONS TO VACCINE INFORMATION SHEETS (VIS)

Objective: To assess reaction to VIS and the degree to which they may shift opinions about diseases and vaccines.

The overall reaction to the sheets was favorable. The quantity and quality of the information contained in the sheets positively impressed respondents.

“These are the most informative sheets I’ve ever seen. The ones that they give out, they don’t show the risk or anything like that. And they give it to you after you have already had the baby.”

HAEMOPHILUS INFLUENZAE VACCINE

Overall Opinion of Hib VIS

The overall reaction to the Hib VIS was positive. It was described as informative and straightforward, and written in words that were easily understood.

The sheet was rated as a “3” on a scale of 1-5, where 1 was easy to understand and 5 was hard to understand.

Generally, respondents agreed that using numbers and statistics to illustrate or clarify a point was a more effective way to communicate.

“Small could mean 50%.”

“A number indicates more research.”

Preferred Additional Information

A description of the disease itself, how to become immunized if you have already missed the outlined schedule, and symptoms of the disease were the areas respondents would augment.

Most Important Piece of Information

Respondents identified the following pieces of information as most important on the Hib VIS.

- Who to call if something happens
- Prevents germs that pass from person to person.

“It is very important to know what it is preventing.”

- Compensation for injuries related to the vaccine
- Ages for immunization.

Respondents generally agreed that while the VIS cited effects of the disease, it did not define the disease. After reading the VIS, respondents continued to complain that they did not know what Hib is.

Favorably Received Information

New and Valuable Pieces of Information

- The severity of the disease.
- Rationale for being immunized
- Age of children who can be affected

Green Highlights

Side effects and what to expect.

“Ask your doctor for details.”

Unfavorably Received Information

Respondents identified a number of areas that were confusing. This was primarily attributable to the lack of familiarity with Hib.

- Confusing phrase
“.....small risk of serious harm.” This phrase was described as vague. This phrase raised more questions than it answered. Respondents wanted to know if people are dying or not and if so, how many.
- Inconsistencies
“.....small risk” followed by “most people don’t have any problems”. Respondents found this contradictory, i.e., “either you have problems or you don’t have problems.
- The dosage description was confusing
The VIS cited the dosage as 3 or 4 doses. Respondents did not understand that it was a specific dosage tied to the brand selected by the physician.

“Well how do you determine that. Why so many times, why can’t you tell me why it’s so many times and why it would be three or four? Like three for young kids 2 months to 4 months and four for this, and why so many times....that’s what I would want to know.

- Confusing language
“3 or 4” times also created the impression that those describing the recommended dosage were unclear about what was required. This confusion was tied to the section “Who should get it and when”. It was explained to respondents that the number of doses was a function of which brand was used by the doctor.
- Perceived contradictory statements
“As with any medicine, vaccines carry small risk of serious harm...” followed by “the risk of the vaccine is much smaller than the risk from the disease.”

Red Highlights

The following phrases were perceived to be confusing or negatively received:

The term “special” was misunderstood. It was interpreted as possibly meaning “heart problems, something minor something major.”

There was no understanding of the word haemophilus. Respondents wanted to know what it is and what it derived from. The perception was that it lacks history.

The phrase, “some people should not get Hib vaccine, or should wait” was said to be confusing. Respondents did not understand the rationale for either status. The statement was said to position the vaccine as optional.

Information was lacking and presented circuitously. In #5, there was the phrase “moderate or severe reaction.” The reader was directed to #4, which says “mild problems”. Neither was adequately explained.

Reference to the disease without an adequate explanation of the disease generated criticism. In #4 there is a statement that “the risk from the vaccine is much smaller than the risk for the disease.” Respondents agreed that they do not know what the disease is.

Direct Appeal to African Americans

Respondents were asked whether it would be important and/or positive to have a disease pointed out to them that skews higher among African Americans. Respondents cited sickle cell and lupus as diseases that affect African Americans disproportionately. The group agreed that seeing the statistics that indicate which races/ethnic groups are most affected by the disease would be positively received.

Vaccine

Awareness

There was negligible awareness of the Hib vaccine. There was even a question of whether their own child had been immunized. Respondents questioned whether it was related to a flu shot, given the word “influenza” in the name. Respondents made the connection to flu shots citing that it is called a shot for influenza.

Respondents felt that the name itself diminished the degree to which they took the diseases seriously. One respondent did distinguish Hib from “Just another flu” because of the spelling.

“When I saw influenzae, it’s not really the same, because this one has an “e” on it. And, influenza is just with an “a” at the end. When I saw it, I thought flu also.”

The Hib VIS information was said to be believable. In addition, it was a cause of concern, because the low levels of awareness. On the other hand, the degree of concern about the disease was seen as minor because of the lack of publicity associated with the disease.

“I am curious as to why this is not public knowledge, more publicized than now.”

“Everybody may get it, but apparently they are not too concerned about it because they are not talking about it.”

The question was raised whether the disease was more prevalent in the African American community or whether it affected Whites more.

Schedules

The schedule was said to be confusing. Respondents were generally displeased with the way some of the information was presented. The statement below raises a caution for those communicating to consumers, that unlike health professionals, they do not generally think about branded vaccines.

“I didn’t like that it said this dose is needed for most vaccine brands. What are you talking about? What vaccine brands?”

Respondents were unaware of how many doses their children were getting of any particular vaccine. Seeing the number of doses required for the Hib highlighted their confusion. In addition, the wording that included 3 or 4 doses for each shot, led to an interpretation of large doses each time the child was scheduled for immunization. This was not the intended message.

Disease

New Information

The severity of the disease was new information for the group.

Source of VIS

Respondents cited a number of places where Hib information might be in order for them to be made more aware of the disease and vaccine. Among those were:

- subway
- television
- newspaper
- baby cereal boxes

Respondents agreed that they would read the VIS. However, the VIS should be distributed in the doctor’s office, or in baby/pregnancy books to encourage readership. Mailing was rejected.

Visual Appeal of VIS

The editorial format, i.e., questions and answers, was said to motivate readership.

CHICKENPOX VACCINE

Overall Opinion of VIS

The VIS was favorably received primarily on the strength of the information presented. Several respondents were unaware of a Chickenpox Vaccine.

On a scale of 1-5 where 1 is hard to understand and 5 is easy to understand, respondents gave the VIS a “5”. This was primarily attributable to familiarity with the disease.

“You can relate, you’ve had it before, you know what it is.”

Respondents agreed that they rated the VIS favorably overall because they do have some familiarity with the disease and found the information useful but not shocking.

Most Important Piece of Information

The following pieces of information were cited as the most important pieces of information in the VIS.

- The disease can still be contracted even though you have been immunized.
- Reasons not to get the vaccine, e.g., pregnancy, HIV
- The severity of the disease and what the disease can lead to, i.e., brain damage, death.

Favorably Received Information

New and Valuable Pieces of Information

- Relationship to shingles was unknown.
- The availability of the Chickenpox vaccine

Green Highlights

Shingles

Reasons to wait to be immunized

Recommended age

Unfavorably Received Information

Information perceived to be non-committal was questioned. Respondents wanted to know whether it prevented the disease or not.” The issue appeared to be the qualifiers that were included in the statements relative to the value of the vaccine.

“Chickenpox vaccine prevents chickenpox. Then it says, most people who get chickenpox vaccine will not get chickenpox.”

“If someone who has been vaccinated does get the chickenpox, it is usually very mild.”

Red Highlights

Seizures as a mild problem. This is counter to the general perception of seizures as a severe occurrence.

Vaccine

Schedules

The perception of the schedule from the information provided was prior to age 13. Most believed that it should be done before entering school.

A particularly favorable reaction was generated when an alternate schedule was made available.

“Say they did not get it, they show a time when you can get it.”

Disease

New Information

The severity of the disease was new information for most of the respondents. There was no prior knowledge that one could die from Chickenpox.

Agency Sponsorship

CDC, followed by DHHS was the name combination most recognized and respected by the respondents. CDC was said to be able to stand alone. DHHS however, was not able to stand alone. The National Immunization Program had no name recognition.

◆ Dept. of Health and Human Services

There was no consistent opinion of what this department stood for. Initially respondents said both state and federal departments of the government. This department does have some negative imagery, such as “cut backs”.

◆ National Immunization Services

There was no awareness of this organization. Respondents had no knowledge of what NIP does. A key question was whether it was a new agency.

◆ Centers for Disease Control

This group unanimously selected CDC as the sponsor name that would add the most credibility and most encourage readership. This was said to do most in grabbing the attention of the reader.

CDC was said to be the better, stronger name because it is more specific. Disease prevention was the first thought when hearing the name, followed by testing, vaccines and AIDS. It also triggers thoughts of something deadly if CDC contacted one directly.

**CHILD IMMUNIZATION STUDY
FOCUS GROUPS WITH AFRICAN AMERICANS
NEW YORK CITY
8:00 PM October 28, 1997**

Moderator: Barbara Hairston

HEPATITIS B/MMR

I. RESPONDENT PROFILE

There were ten respondents in the group, seven (7) females and three (3) males. All were parents of young children, ranging in age from one month nineteen years.

The family composition of the respondents tended more toward single parenting and less traditional living arrangements. Specifically, rather than two parents and child(ren), the respondents either lived alone with their children, with a sibling and the sibling's child, at home with parent. Time was a key barrier which respondents identified as the reason they were doing very little to take care of themselves.

II. ATTITUDES AND PERCEPTIONS OF VACCINES

Objective: To gain insights into respondents' attitudes and perceptions of childhood diseases and vaccines.

Awareness of Vaccines

Respondents knew several of the vaccines which are available to prevent childhood diseases. Some of this awareness or top of mind mention of some may be attributable to the fact that the respondents read two VIS prior to the discussion. The list generated by the respondents was very limited beyond what was read in the group.

Hepatitis B	Diphtheria
Flu	Measles, German Measles
Mumps	Small Pox

The word "vaccine" tended to trigger thoughts of a positive outcome as well as the process and purpose of vaccination.

<u>Purpose</u>	<u>Process</u>	<u>Positive Outcome</u>
Protection	needles	good health
Disease prevention	dead germs	immunity
Exposure to germs	doctor	

There is an emotional component to vaccines and immunization. Generally, respondents agreed that vaccines make them feel safe.

“Because being vaccinated means being protected against diseases that can cause death, that can be fatal.”

“To be immunized means you are protected across the board from these diseases that can cause major damage to the brain, liver, your health in general.”

The feeling of safety did not offset the fear some respondents felt knowing that “there is so much disease out there” in the first place.

Immunizations – Required Or A Parent’s Choice

Immunization is a requirement rather than a choice. All of the respondents said that they themselves immunize their children. One of the most important motivators was the requirement that children be immunized prior to attending school.

When Others Do Not Immunize

Respondents identified several reasons why some people do not immunize. These included:

- Stupidity
- The fear of side effects. “Some feel there is a risk, that the child might not react well to the medicine.”
- Lack of education. This was primarily attributed to those who are from other countries where immunization is not stressed or may not be available.
- Preference for natural or holistic health practices.

Safe or Risky

Vaccines and immunizations were characterized as more safe than risky.

“Safe enough, I didn’t conjure up any fears that were not presented to me. So far, I feel safe but I know there are risks.”

“The risk from the vaccine is less than the disease itself without the vaccine. Some things you have to see what outweighs what.”

Areas of Confusion

Respondents generally felt that they both understood and misunderstood some aspects of vaccines. Though most said they read constantly, the information currently available was perceived to be inadequate. The information on the VIS viewed as much more comprehensive than other material they had read to date.

“No matter how much you read, there is never enough information.”

Source of Information about Vaccines and Immunizations

Respondents were relying on traditional sources of information. Most had obtained information from doctors, flyers doctors had around the office, their own mother, children's magazines, and Parent's Magazine.

Alternate Sources of Trusted Information

Respondents suggested a limited number of alternate sources of information. The one most agreed upon was the regular health feature that appears on news programs. Regular news was rejected because of the regularity of retractions.

Preferred Form and Timing of Information

A key complaint of some of the respondents who were also new mothers was the fact that doctors tend to provide information about immunizations at the time of the immunization. The complaint is that this does not give the mother adequate time to understand the implications nor to make informed decisions if a choice is involved. Some believed that information is withheld in order to minimize the chance that parents will become too emotional.

“They should tell you before and after to let you know what you should look out for.”

II. REACTIONS TO VACCINE INFORMATION SHEETS (VIS)

Objective: To assess reaction to VIS and the degree to which they may shift opinions about diseases and vaccines.

MEASLES, MUMPS & RUBELLA

Overall Opinion of Measles, Mumps & Rubella VIS

The measles, mumps and rubella VIS generated an overwhelmingly favorable reaction from the group because of the quality and depth of the information presented. This sheet was characterized as very informative.

"The information that I usually get about this is usually given to be when my child is being vaccinated. Not that much in depth on the side effects. This goes into depth on the side effects."

The VIS was viewed very favorable for communicating the information required for a parent to make an informed decision about immunization.

Respondents were able to clearly distinguish between those symptoms related to the disease and those related to the vaccines.

Most Important Piece of Information

The section entitled "Why You Should Get It" was cited by several respondents as the most important piece of information. The severity of the diseases was also cited as new and important information.

"I wasn't aware of the effects of any of these diseases"

If you think measles are just an itch, but you know ear infection, diarrhea, pneumonia, brain damage, death, that's something else to think about."

However, it was also the severity of the effects of the disease that led respondents to question the credibility of the information. Citing their own experiences during which they remembered only a rash being associated with measles, and at most a fever.

The presence of the CDC logo was said to restore credibility because of the respect these respondents have for that organization.

"CDC on the back makes it good enough for me."

Favorably Received Information

New and Valuable Pieces of Information

Respondents circled almost every section of the MMR VIS to indicate that there was new and important information. Respondents were generally favorably impressed with the depth and breadth of information.

Unfavorably Received Information

When information was unfavorably received, it was typically because it was not consistent or seemed to contradict information previously presented. For example, when information was presented qualitatively, e.g., "small risk," respondents wanted to know what that meant quantitatively, e.g., 1 out of 100,000. This issue was also cited when problems were described as "common" or "very rare."

There was some confusion about the information presented in Section 3: Some People Should Not Get MMR or Should Wait. The either/or premise confused respondents as did the conditions for rejecting or waiting to get the vaccines.

HEPATITIS B

Overall Opinion of VIS

The information provided in this VIS was favorably received. Respondents viewed almost all of the information as new and important. There were limited indications of any information that was viewed as confusing.

Favorably Received Information

New and valuable Pieces of Information

Respondents seemed less informed about hepatitis B, and as such indicated that most of the information presented was new and valuable. Transmission of the disease generated discussion particularly the idea that sharing personal items could spread it. The idea of sharing a toothbrush was offensive as well as new and valuable.

Green highlights

Respondents tended to concentrate their indication of new a valuable information in Sections 1-3.

Unfavorably Received Information

The information, which was unfavorably received, was generally that which was confusing to respondents. The caveat here is than some information, which was new, was sometimes characterized as confusing.

Red Highlights

Two issues related to allergies were indicated as confusing. First of all, respondents were unfamiliar wit the term "bakers yeast." Some went as far as to try to connect it to a yeast infection. Others questioned the connection between an allergy to gelatin and a vaccines.

The chart entitled "When Infants Should Get Hepatitis B Vaccine" generated some confusion when the caption related to the mother's infection were not read or misread. One respondent simply started with the first column. With the help of the group, she understood the difference.

**CHILDHOOD IMMUNIZATION STUDY
SPANISH-SPEAKING HISPANIC GROUP
NEW YORK CITY
6:00 PM October 29, 1997**

Moderator: Jorge Cherbosque

HIB/CHICKENPOX

Attitudes and Perceptions of Vaccines

Respondents' associations with the word "vaccine" included:

- Injection
- Children
- Illnesses
- Medicine
- Pain
- Children screaming
- Something necessary
- Fever
- Something serious
- Something to prevent illness

Respondents indicated that they see vaccinations as required, obligatory, and not an optional parental decision.

Mandatory vaccinations were preferred by respondents, some of whom said they could not trust other parents to be responsible for their children's health.

Overall, respondents said they saw no risk in vaccines. They said they believed that the government would protect their children's health by studying possible effect in depth. Their personal experiences with vaccines also led them to conclude that these inoculations are safe.

Respondents said they understood both the process and purpose of vaccinations.

Parents who participated in this focus group stated the following sources for medical information:

- Hospitals
- Medical offices
- Pediatricians
- Magazines

A significant minority (about one-third) of participants said it was essential that information be made available in Spanish.

Respondents listed the following as other trusted sources of information:

- Doctors
- Hospitals
- Mothers
- Nurses
- Reputable television reporters

Reaction to the Vaccine Information Sheets

HIB VACCINE

Only one respondent was aware of Hib. No respondents were certain that their children had been immunized for it.

Respondents said they liked the question and answer format and said the information sheet was:

- Informative
- Very clear
- Easy-to-understand
- Easy-to-read

Additional information sought by respondents included:

- More information about and a description of the illness itself
- How the illness spreads
- What determines who gets Hib (genetic vs. environmental factors)
- Notice that you could get the vaccine later in life if you had not received it as a child

On a 1-5 rating scale (1 = easy-to-understand), respondents rated this information a 2 rating.

Respondents said the most important information they received from this sheet was:

- Why it is important to get the Hib vaccine
- What happens to you if you get Hib
- The vaccination schedule
- Side effects

Overall, respondents understood that the risk of getting this illness is, by far, more severe than the risk of side effects.

Among the terms and/or concepts about Hib that were not clear to respondents were:

- The description indicating that some adults with “special problems” was too vague and needed clarification.

- The word “urticaria” was unknown. “Salpullido” was a suggested replacement word by one or two respondents.
- “Choque” was said to be confusing as it was not associated with a medical disease.

Overall, respondents said that the information presented on the sheets was clear and believable. They said they would prefer statistics over words in explaining complications. They noted that statistics imply scientific research. This enhances the information’s validity and trustworthiness.

Respondents indicated that they would not eliminate anything from the information sheet.

CHICKENPOX VACCINE

Respondents said that most of this information was already known to them. They found the information to be very clear, complete, educational, and relevant.

Some of the new information included:

- The vaccine can be administered to children over age 13 and to adults.
- The schedule of vaccinations
- That under certain conditions, some individuals should not receive the vaccine

Words unknown and/or unfamiliar to respondents included:

- “Salpullido” (rash)
- “Urticaria” (rash)
- “Choque” (shock)
- “Zoster” (shingles)
- “Mirada fija” (fixed stare)

The following represents information that respondents found to be most useful:

- The names and phone numbers of the three organizations
- Internet access to information
- Explanations about why one should get the vaccine
- Explanation of side effects
- Clarification as to why one should not get the vaccine

Some respondents were confused about the number of dosages. Some thought three dosages were necessary; one between 12 and 18 months and two more after age 13. They did not understand that the information sheet was referring to different situations. This should be clarified on the information sheet.

New learning from the information sheet included the fact that shingles could be a consequence of having chickenpox.

Respondents indicated that the endorsement of the three agencies increased the credibility of the information sheets. They were most familiar with the Department of Health and Human Services and the CDC. The names of these organizations were said to validate the information.

Respondents wanted to get information about the possible causes of chickenpox.

For the most part, respondents said they expected to find information in hospitals, doctors' offices, children's magazines, and on the Internet. The majority of respondents said that the best time to receive this information is during pregnancy when women are highly motivated and open to new information.

Overall, respondents liked the way the information sheet looks. They said it was informative and easy-to-read. They did, however, suggest adding a photograph of a smiling child.

**CHILDHOOD IMMUNIZATION STUDY
BILINGUAL HISPANIC GROUP
NEW YORK CITY
8:00 PM October 29, 1997**

Moderator: Jorge Cherbosque

HEPATITIS B/MMR

Attitudes and Perceptions of Vaccines

Respondents' associations with the word "vaccine" included:

- Disease
- Prevention
- Something safe that could become scary

All respondents agreed that vaccinations should be mandatory, not optional. If vaccinations were not mandated, respondents feared that some parents would become lazy, ignore the shots, and risk the safety of their children.

Overall, respondents perceived the benefits of vaccinations to be much greater than the possible risks.

The majority of respondents said they needed more information about different illnesses, how people are infected, risks of the diseases, symptoms, and side effects of the vaccine.

Parents participating in this group stated the following sources for medical information:

- Other parents
- Family members
- Doctors
- Health centers

Nurses were not perceived as trustworthy sources of information.

Reaction to the Vaccine Information Sheets

HEPATITIS B

Reaction to this information sheet was very positive. Respondents said the information was thorough, to the point, easy to read, and easy to understand. They said it was motivating and invited them to talk with their doctors about the disease.

On a 1-to-5 scale, respondents rated this information a 1 or 2 for clarity.

Respondents said they wanted more information or clarification on the following points:

- What can be done to prevent getting hepatitis B
- What are the course and progression of the disease
- Information about treatment options and a possible cure
- What countries/areas are considered high risk

Respondent listed the following as the most important information received via these sheets:

- Methods of transmission
- Symptoms
- Vaccination schedule
- Any serious and/or life-threatening aspects

Most respondents said they wanted a statistical description of possible risks, not verbal descriptions. They said such information would be clearer, more objective and would provide them with a better perspective. For the most part, they felt that words could be vague. They also felt that statistics made them feel that the topic had been researched and that the vaccination process was being supervised.

Respondents said they felt the information sheet provided both the benefits and risks of the vaccine. They indicated, however, that the information did not give them a feeling that the benefits are greater than the risks. They wanted to know, statistically, how many people die from the disease and how many die from the vaccine. This information would calm them, they said, and highlight the benefits of the vaccine.

Respondents said they were confused by information that stated that you could get sick from the illness and/or from the vaccine. They understood this information to mean that both situations could lead to death.

All information on the sheet was considered by respondents to be essential. They did not suggest eliminating anything.

Questions prompted by the information sheet were:

- Am I at a higher risk for hepatitis B because I work with substance abusers?
- What is the course of the illness?
- What is the vaccine? How does it work?

Respondents noted the following as the most essential information:

- Hotline phone numbers
- Vaccination schedule
- Transmission routes of the disease

MMR

Overall, respondents' reaction to this information sheet was very favorable. They found it informative, thorough, easy to read, easy to understand, and relevant. They rated it a 1-to-2 for clarity on a five-point scale.

To make the sheet even more clear, respondents suggested expanding the following:

- How do the rashes look? (Include a picture.)
- Improve the description of "seizure". "Jerking" and "staring" were not complete descriptions for respondents.
- Explain "platelet count."

Respondents cited the following as valuable, new information:

- Symptoms
- Possible brain damage
- Adult receipt of the vaccine
- Vaccination schedule
- Dosage clarification
- That the disease(s) can be fatal

Respondents said the information was convincing, motivating, and believable. They said the comparison between risks and benefits was clearly explained.

The following were noted as locations for obtaining information:

- Doctors' offices
- Hospitals
- Schools
- Day care centers

The best time for receiving immunization was said to be during pregnancy and when children started school.

Respondents said that the information sheet, while easy to read, was not very attractive. About half of them said they would ignore the sheet and suggested the following:

- Add color
- Add photos showing how the different rashes and pink eye look

Most respondents knew about the Department of Health and Human Services. They described it as a place to get tested and where vaccines are given in a free and confidential manner. They were somewhat familiar with the National Immunization Programs and, to a lesser degree, the CDC.

Respondents liked the fact that these organizations had endorsed the sheets. They said this endorsement was a confirmation of the sheet's authenticity and indicated that the information was trustworthy and serious.

Overall, respondents said that, based on the information sheets, they felt they had made the right decision in having their children immunized.

**CHILDHOOD IMMUNIZATION STUDY
VIETNAMESE GROUP
LONG BEACH, CALIFORNIA
1:00 PM November 10, 1997**

HIB/CHICKENPOX

Reactions to Vaccines in General

Respondents associated the following with the word “vaccines:”

- Preventing disease
- Safety
- Important
- Necessary
- Parental choice

They expressed a desire to understand information about vaccinations.

The following were noted as sources of information about vaccinations:

- Health departments
- Doctors
- Schools
- Social services department
- Radio and television (They said the stations should get information from the government.)

Respondents said that information from the government was trustworthy. Information distributed through temples and churches was also said to be trustworthy.

They also placed trust in their family doctors.

Reaction to Vaccine Information Sheets

HIB

Some respondents were aware of Hib and understood it could be fatal. Others, who were unaware, were alarmed about this information.

On a 1-to-5 scale, most respondents rated the information sheet as 1 (easy to understand). They felt the translation into Vietnamese was very clear.

They understood that side effects, especially fever, were possible after immunization.

New information derived from the fact sheet included:

- Symptoms
- Fainting
- Rashes

No consensus was reached about the statistical data on the information sheet. Some respondents liked the numbers; others preferred words. Overall, they felt that this was information only their doctors would understand.

After reading the information sheet, respondents said they were more informed about side effects and complications from the vaccine. They expressed a strong desire to understand the information fully. All felt the information presented was beneficial.

Respondents were confused about contracting Hib itself and having side effects from the vaccine.

CHICKENPOX

All respondents seemed to be aware of chickenpox and understood the information sheet. They rated it as easy to understand on the 1-to-5 scale. All respondents understood that the disease is contagious.

All respondents said they trusted the information on the sheet shown to them. They were aware of the immunization schedule and possible side effects. They also seemed to understand the slight risk of getting the disease from the vaccine. They said the information sheet made this very clear. They were somewhat surprised that chickenpox could be very dangerous for adults.

Overall, respondents said they preferred statistical information and said they would ask their doctors for clarification if necessary.

Respondents said they would like to receive information before going to the doctor. They noted that they sometimes fail to read written information given to them by their physicians. They would like to receive information as follows:

- By mail from the health department
- On radio and television
- In the Vietnamese newspaper (so they could cut it out and post it at home)
- From schools and school nurses

Respondents suggested that the print be a bit smaller. They agreed that they needed to read health information but only if they had time.

No one in the group was aware of the Department of Health and Human Services, the National Immunization Program, or the CDC.

Overall, respondents said they wanted information in Vietnamese, especially in Vietnamese newspapers.

Some respondents commented that vaccines had been available in Vietnam but not administered unless “they made some money out of it.”

**CHILDHOOD IMMUNIZATION STUDY
VIETNAMESE GROUP
LONG BEACH, CALIFORNIA
3:00 PM November 10, 1997**

HEPATITIS B/MMR

Reactions to Vaccines in General

Respondents associated the following with the word “vaccines:”

- Healthy
- Prevention

Respondents said that because some people have allergies or get side effects, a rash is not too important. They said they would check with their doctor if a rash appeared.

Respondents said the immunization was required when they first came to the US. They said that immunization should be required, not optional.

Trusted sources of information:

- Reminders with check-up
- School
- Clinics
- Doctors
- Health department
- Posters
- Radio and television ads

Reaction to Vaccine Information Sheets

HEPATITIS B

Respondents said this information sheet was very important to the Asian community which, they said, is a high risk group.

Respondents were concerned that hepatitis B could be spread by dipping their chopsticks into a communal pot.

All respondents agreed that there should be no choice with regard to immunization. It must be mandatory. People should be told about the dangers.

Overall, respondents said that most of the information sheet was clear and easy to understand. They were unclear about the concept that relates the consequences of missing a dose or not following the vaccination schedule.

New learning from the information sheets included:

- Information stating that hepatitis B can cause death or miscarriage
- A government-sponsored compensation program
- Sanitary considerations (e.g., using the same toothbrushes and/or razors)

The most important information they received from the sheet was:

- The vaccination schedule
- Benefits of the vaccine
- Consequences of not getting the vaccine
- Transmission of the disease

All respondents wanted to receive information in Vietnamese. They said that English-language materials would not interest them.

Changes suggested by respondents included the addition of color.

Respondents said that this information should be made available in hospital waiting rooms, in doctors' offices, and at bus stops.

This information was said to be believable. Respondents agreed that the sheet explained the difference between getting the disease itself and getting it from the vaccine,

MMR

Respondents found this information sheet to be very helpful. They said it was believable and that they learned from it.

Churches and Buddhist temples were said to be trustworthy sources of information. Health Department offices were also said to be reliable sources. Respondents suggested that information be disseminated via broadcast media because, they said, many people do not have time to read newspapers or pamphlets. They also noted that many people listen to the radio while they are working.

The respondents said they expected to find this information at the following:

- Doctors' offices
- Clinics
- Schools
- Churches

Overall, respondents felt that vaccination for MMR should be mandated. They did not, however, seem to understand if this vaccination was primarily for children or for adults.

New learning from this information sheet included:

- Some people should not get the MMR vaccine.
- People with HIV-AIDS are unable to fight infections and, therefore, might be susceptible to disease after vaccination.
- Miscarriage and/or birth defects could be side effects of vaccination.

These Vietnamese respondents said that information about immunization should be received as soon as possible so that they can mentally prepare for these inoculations. They also said it would be helpful to distribute the information at their children's schools.

Suggested additional/improvements to the information sheet included:

- Larger, more eye-catching titles
- Pictures
- Tri-folded for ease and ability to slip into pockets
- Offer a Vietnamese-English bilingual 800 information line.

About half of the respondents were familiar with the Department of Health and Human Services. They were not aware of the National Immunization Program or the CDC.

Endorsement by the Department of Health and Human Services indicated that the information was trustworthy and authentic.

**CHILDHOOD IMMUNIZATION STUDY
SPANISH-SPEAKING HISPANIC GROUP
LONG BEACH, CALIFORNIA
8:00 PM November 10, 1997**

Moderator: Jorge Cherbosque

HEPATITIS B/MMR

Attitudes and Perceptions of Vaccines

Respondents' associations with the word "vaccine" included:

- Pain
- Prevention of illness
- Children's health
- Security for parents

Respondents indicated that vaccinations should be required, not optional. They said the optional vaccination might victimize children and increase the risk of illness.

The majority of respondents agreed that vaccination was generally safe but understood there were some risks. All respondents agreed that the benefits were much greater than the risks.

Overall, respondents requested more information about vaccinations. They wanted to know:

- What a vaccine is and how it works
- Risks of contracting the illness from the vaccine
- Symptoms and potential side effects

The most trusted information respondents said they received is from:

- Doctors
- Vaccination campaigns
- Health centers, especially women's health centers

Reaction to the Vaccine Information Sheets

HEPATITIS B

Respondents found this information sheet to be very informative, thorough, easy to read and easy to understand. On a 5-point scale, they rated it as 1-to-2 for clarity.

Concepts cited as unclear were cited as:

- Why are three doses administered?
- What is the purpose of each dose?
- Why is it not possible to give the vaccine in only one dose?
- What are the consequences of missing a dose or not following the vaccination schedule?
- Why should people who are seriously allergic to baker's yeast not get the vaccine? (Respondents did not understand the correlation between risk and baker's yeast.)

Respondents wanted to know in which countries hepatitis B is common.

Some of the medical terms on the information sheet were confusing to respondents:

- "urticaria" (Respondents suggested "intoxication" or "salpullido" (rash).)
- "choque" (Some respondents understood this to mean a nervous breakdown. Others perceived it as a convulsive episode. They suggested describing it as "loss of consciousness.")

Respondents said the following was the most important information they received:

- Vaccination schedule (three doses)
- Benefits of the vaccine
- Consequences of not getting the vaccine
- Transmission of the disease (especially via toothbrushes)

Overall, respondents said they would prefer a verbal description of the risks of serious side effects, rather than statistics. They said they would understand better. It would reduce their anxiety levels.

This information sheet was said to be believable. Respondents agreed that the sheet explained the difference between getting the disease itself and getting it from the vaccine.

All information on the sheet was considered to be essential. Respondents wanted nothing eliminated.

MMR

Respondents found this information sheet to be very informative, thorough, easy to read and easy to understand. On a 5-point scale, they rated it as 1-to-2 for clarity. They suggested the following changes:

- Clarify the differences between measles and rubella.
- Clarify the meaning of "envoltura del cerebro" (brain covering).
- Reconsider "sacudidas con mirada" (jerking and staring). Some respondents indicated observing "una mirada perdida" (a lost stare), not a fixed stare.
- Explain repercussions of allergy to gelatin with regard to the vaccine.
- Clarify and/or re-translate "urticaria" (hives), "choque" (shock), and "espasmo muscular" (jerking).
- Platelet count and steroids were also unclear.

New learning from the information sheet included:

- National Vaccine Injury Compensation Program
- Risks for pregnant women
- Possibility of mumps being fatal

Respondents acknowledged the information as believable. They said the comparison between benefits and risks were clearly defined. They expected to receive this information at the following:

- Doctors' offices
- Clinics
- Schools
- Churches

Respondents indicated that the timing for receiving information is very important. They said the best time for distributing information is during pregnancy or at the moment of discharge from the hospital. They also said it should be distributed at their children's schools. If their doctor mandates or recommends the reading of this information, respondents said they would be very likely to read it.

While they agreed that the information sheet was easy to read, respondents felt that it was "sad-looking" and unattractive. They suggested the following changes:

- Addition of color
- More drawings and/or photographs (e.g., a healthy child compared to one who is symptomatic)

After reading the information, respondents felt reinforced about making the decision to have their children vaccinated. They felt they had made the right decision.

About half of the respondents were familiar with the Department of Health and Human Services. They were not aware of the National Immunization Program or the CDC.

Endorsement by the Department of Health and Human Services indicated, according to respondents, that the information was serious, trustworthy, and authentic.

**CHILDHOOD IMMUNIZATION STUDY
BILINGUAL HISPANIC GROUP
LONG BEACH, CALIFORNIA
6:00 PM November 10, 1997**

Moderator: Jorge Cherbosque

HIB/CHICKENPOX

Attitudes and Perceptions of Vaccines

Respondents' associations with the word "vaccine" included:

- A shot
- Prevention of illness
- Medicine
- Crying
- Mandated by the schools

Respondents indicated that vaccinations would be required, not optional. They said the optional vaccination might be considered like gambling with their children's health and safety.

The majority of respondents indicated that they perceive the process of vaccination as basically safe, with only some risks. They perceived the benefits as out-weighting the risks.

About half of the participants in this group said they did not have information about the vaccination process. They especially wanted more information about potential side effects and how to recognize them. Respondents felt that information was more readily available to people with private physicians than those who go to clinics.

Respondents' most trusted sources of information included:

- Magazines (*Parent, Child, Sesame Street*)
- Doctors
- Pharmacies
- Schools
- Day care centers

HIB

Respondents found this information sheet to be very informative, thorough, easy to read and easy to understand. On a 5-point scale, they rated it as 1-to-2 for clarity. They suggested the following changes:

- Explain why their children need repeated doses of the vaccine

- What are the objectives of each stage of vaccination?
- Why is the vaccine not potent enough to be given in one dose?
- Are there different brands of vaccines? If so, is one brand better than another?

Respondents said there is a need to reinforce the benefits of Hib vaccination as contrasted to the risks. To do this, respondents said, parents need to be informed about the consequences of Hib itself.

The most important information contained in the sheet was cited as:

- Learning that Hib can be fatal
- Some people should not receive the vaccine
- How Hib is transmitted

Most respondents said they preferred statistical information over verbal information regarding the benefits and risks from vaccination. They felt that statistics provided a better perspective of the possible risks. A significant minority of respondents said that statistics would heighten their anxiety about the vaccine.

All respondents said the information presented was believable and that the comparison between benefits and risks were clearly explained. They were, however, often confused about the possibility of getting Hib via transmission and getting the illness from the vaccine.

All information on the sheet was said to be essential. Respondents did not indicate any information that should be eliminated.

CHICKENPOX

Respondents found this information sheet to be very informative, thorough, easy to read and easy to understand. On a 5-point scale, they rated it as 1-to-2 for clarity. They suggested the following clarifications, explanations and answers:

- Clarify and define “shingles.”
- Explain problems associated with allergy to gelatin.
- Explain how the disease is transmitted.
- Clarify the contagious period and advise how to know if someone is no longer contagious.
- If you are pregnant, can you be around a child who has chickenpox?

Respondents said the fact sheet contained the following new information:

- Persons over age 13 could take the vaccine if they never had it or chickenpox in the past.
- Explanation of side effects
- Some people should not receive the chickenpox vaccine.

Respondents said the information presented in the sheet was believable and that the comparison between benefits and risks was very clearly explained.

Respondents said they expect to get this information via:

- Doctors’ offices
- Pharmacies

- Schools
- Newspapers
- Churches

Respondents indicated that the timing for receiving information is very important. They said the best time for distributing information is during pregnancy or at the moment of discharge from the hospital. They also said it should be distributed at their children's schools.

Although they found the information sheet easy to read, respondents said it was unattractive. They also said the graphics were "infantile." They suggested the following changes:

- Highlight relevant information in bold (e.g., consequences of not taking the vaccine)
- Include photos that illustrate the illness and its symptoms

Approximately half of the respondents knew about the CDC, but were not aware of the Department of Health and Human Services or the National Immunization Program. The endorsement of these agencies made respondents aware that the information sheet was serious and trustworthy. Respondents perceived this endorsement as a seal of approval.

Based on this information, respondents felt they had made the right decision in giving the vaccines to their children.

**CHILDHOOD IMMUNIZATION STUDY
CANTONESE-SPEAKING CHINESE
PASADENA, CALIFORNIA
6:00 PM November 11, 1997**

HIB/CHICKENPOX

Attitudes and Perceptions of Vaccines

The major association that respondents made to “vaccination” was “shots.” They suggested using the Chinese word for “shots” instead of “vaccinations.”

Respondents felt that immunization was necessary to prevent future illness. Some respondents were unaware that there was any risk associated with vaccines. Overall, they felt that the benefits outweighed the possible harm from side effects.

Sources of information about immunization were listed by respondents as:

- Doctors
- Schools (especially prior to entering kindergarten)
- Pharmacies
- Television (then verify with own doctor after seeing on television)

Reaction to the Vaccine Information Sheets

HIB

On a rating scale of 1-to-5, most respondents rated this information in the 2-range. While they said the sheet was easy to understand, they were confused about several issues:

- Pericardium – Respondents did not understand “covering of the heart” or “covering of the spinal cord.” They suggested using the Chinese word () to describe the word “covering,” (e.g.,) for heart wall covering and () for spinal cord covering.
- Some respondents understood what hives are. One respondent thought they were like some sort of measles.
- The sheet offered no symptoms; only described what happens after one contracts Hib.
- Section 2 of the sheet discussed adults with “health problems.” Respondents wanted to know what those problems are and wanted them stated specifically.

These Cantonese-speaking Chinese felt that their English-language skills were not good and requested a special telephone number to call for in-language information. This was especially true of those who did not have a family doctor to whom they could address questions.

Overall, respondents felt that all the information on the sheet was important. They said the first section, called “Why get vaccinated?” was especially important. They said it motivated the reader to take action.

Respondents wanted to know more about Hib itself, how it feels to have Hib, and what the possible complications are.

There was no consensus regarding the use of statistics or words for noting possible risks of getting Hib from the vaccine. Respondents felt that showing numbers might cause some people to take a chance, like gambling, especially if the risk of getting it is very small (i.e., one in a million).

Respondents believed that some parents, especially those who recently immigrated to the US, never care about vaccinations or immunizations for their children because they are not informed.

Respondents were aware of side effects, like fever, but said the shots are beneficial. Many agreed that the benefits of vaccination outweigh the risks. Some respondents took a rather fatalistic stand, saying that they could die with or without the shot.

CHICKENPOX

Information sheet items that respondents said were particularly important were:

“Why get vaccinated?”

“Chickenpox Vaccine”

“Some people should not get chickenpox vaccine or should wait.”

“The National Vaccine Injury Compensation Program”

As noted earlier, a Cantonese-speaking 800 information line was considered important. Respondents were not interested in Internet information, as most did not have access to it.

Respondents indicated that the Chinese translation was clear and told them things they had not known before. They said this information sheet was easier to understand than the one about Hib.

Suggested improvements included adding color to make the sheet more attractive. Respondents also suggested adding photos of a child who had chickenpox.

All respondents said that all the information was important and credible. A few respondents were aware that adult chickenpox is very serious.

Respondents said they expected to find this information at:

- Doctors’ offices
- Schools
- Pharmacies
- Markets
- Churches

With regard to the timing of information distribution, respondents said that the best time would be at, just after a child's birth, or during the first doctor visit after birth. They said it was the mother's responsibility to take care of these shots.

Awareness of Health Organizations

Respondents were not familiar with the Department of Health and Human Services, the National Immunization Program, or the CDC.

Respondents agreed that prevention of illness is important. They felt that immunizations should be required by the government.

**CHILDHOOD IMMUNIZATION STUDY
CANTONESE-SPEAKING CHINESE
PASADENA, CALIFORNIA
8:00 PM November 11, 1997**

HEPATITIS B/MMR

Attitudes and Perceptions of Vaccines

Respondents' associations for the word "vaccination" included:

- Prevention
- Injection

Overall, most respondents thought that immunization should be required. The consequences of not being vaccinated included getting the disease. They understood that vaccines contained some bacteria that were injected into the body.

Most respondents felt that vaccines are safe.

Sources of information about vaccines included:

- Word-of-mouth information from friends and family members
- Schools
- Doctors
- Insurance companies

Reactions to Vaccine Information Sheets

HEPATITIS B

Most respondents rated this information as 2 on a 1-to-5 rating scale. Thus, they found it fairly easy to understand.

Primarily, respondents wanted to know how the disease was transmitted and how they might get it. They wanted an understanding of the various types of hepatitis B. They did not understand the relationship to baker's yeast.

Overall, respondents felt the two most important items on the information sheet were:

"How is hepatitis B spread?"

"Who should get hepatitis B vaccine and when?"

Respondents were aware that Southeastern Asians were susceptible to hepatitis and noted that some people tend to be passive carriers of this disease.

Symptoms of hepatitis B were listed by respondents as:

- Muscle spasms
- Noticeable differences in eyes and skin

A few respondents said they preferred statistics in noting the risks involved with the vaccine. Most of them, however, said that words would help them to remember the information better.

Some respondents were confused about the risk of reaction to the vaccine. They confused it with the services of the National Vaccine Injury Compensation Program. Overall, they agreed that their doctors would advise them of what kind of reaction to expect and how to treat it.

Respondents said that information about immunizations should be given to all couples of child-bearing age, during pregnancy, or immediately after birth. Overall, they felt that getting the information as early as possible would be beneficial.

All respondents wanted to get information in Chinese.

Suggested additions to the information sheet included:

- How would one get hepatitis B? From food (i.e., particular kinds of food like certain seafood)?
- Statement of the term of the immunization. It is for a lifetime?
- Clarifying risk factors
- Information on other types of hepatitis B

Some respondents believed that hepatitis B was spread through food contamination. They wanted this issue addressed and clarified on the information sheet.

MMR

While respondents rated the information a 2 on a 1-to-5 scale, they exhibited confusion about measles, mumps, and rubella. They did not understand either the diseases or the medical terms. Some respondents did not know what a platelet is; others asked if German Measles was an early stage of AIDS.

Respondents understood the translation but expressed concern that experts cannot agree on the risks. That experts are not sure that brain damage can occur was considered by some respondents to be the worst risk. They suggested changing the information to say that medical studies do not agree about the risks.

Respondents said they would expect to receive information about immunizations from:

- Newspapers (Chinese and English-language)
- Mail
- Schools
- Libraries
- Chinese community centers
- Clinics
- Broadcast media

- Mobile units in their own communities

Suggested improvements to the information sheets included:

- Adding color
- Including pictures that illustrate the symptoms
- Reducing the size for more convenient reading (e.g., a booklet form)
- Placing the information in the Chinese Yellow Pages

Awareness of Health Organizations

About half of the respondents were aware of the Department of Health and Human Services. Only a minority knew of the CDC and the National Immunization Program.

**CHILDHOOD IMMUNIZATION STUDY
FOCUS GROUP WITH NON-HISPANIC WHITE PARENTS
BALTIMORE, MARYLAND
10:30 AM November 13, 1997**

Moderator: Wendy Child

VACCINE INFORMATION SHEETS REVIEWED BY THIS GROUP:

(1) Haemophilus influenzae type b (Hib) Vaccine; and (2) Varicella (Chickenpox)

PARTICIPANTS:

10 parents including 9 mothers and 1 father.

SUMMARY OF FINDINGS:

Participants' associations with the word "vaccine":

Early in the group, participants were asked to talk about what comes to mind when they hear the word "vaccine". There was a general sense that it is wise to get recommended vaccines, but there were some negative associations with the word and concerns both about whether they are safe and whether doctors provide enough information. Participants reported the following associations:

*"Needle";
"Cranky baby";
Fear about whether "you're being used as a guinea pig";
Concern about whether there is a "political motivation for vaccines becoming required";
Sense that some doctors are unwilling to answer questions about vaccines (while others provide fairly extensive information);
Some sense that some vaccines are unnecessary; and
Experiences becoming ill after flu shot.*

The following comments illustrate some of the opening discussion:

"You know it's better to have any type of vaccine but it's still scary because you don't know if you're being used as a guinea pig."

"I don't want to take a chance [on getting the disease] even though it might not be a good shot. Nowadays, there's everything popping up...it's better to be safe than sorry."

"...I wanted to know more about [the vaccine my daughter was getting] and her doctor gave me a fit...I said 'I want to know more' but [the doctor] just said 'She has to get them...'"

“Doctors push you to make your children have these shots and a lot of them are unnecessary to me...Growing up, I never had half these shots.”

“I went for a flu shot and haven’t been right since.”

A few participants also mentioned that they would like to have more information about the vaccines. For example:

*“They should put out more as far as the **side effects**.”*

*“I think there ought to be a list of the shots that are **mandatory** and the ones that are **optional**.”*

*“They should send something out about **who’s been affected** from these vaccines badly and who hasn’t. The state should give these out so we know what’s going on as far as these shots go.”*

Sources participants reported for information about vaccines:

Participants said the information they have now about vaccines came from:

Mothers;
Doctors;
Schools;
The news; or
Children’s immunization record books.

There seemed to be general agreement that **information from the doctor is most credible**. However, some participants also voiced concern later in the discussion about whether they could trust the doctor. For example:

“You don’t know if you can really trust your doctors enough...The first thing they ask you is what kind of insurance you have...doctors will get you to come back in more and more times for money.”

General Response to Hib Vaccine Information Sheet:

There was general agreement that the Hib information sheet provided good information and was easy to understand. A few people thought it might be difficult for teen parents to comprehend, but no one in this group said it was confusing to them. There were some things that participants said they wanted **more information** about. For example:

Side effects:

More detail about potential side effects, especially because “*death*” is identified as a potential side effect;

Information about the number of people who die from the disease to compare with the number of people who die or have “*longterm conditions*” from the vaccine; and More numbers in general instead of words such as “rare” or “common.”

“Special health problems”:

One participant wanted more information about the reference to “adults with special health problems.”

What participants reported learning about Hib from the information sheet:

A few participants said they had never heard of Hib and asked questions such as:

“How many people die of it? Who gets it? Where does it come from?”

“What can happen if you don’t get the shot? I want to know what it was, where it came from, how it originated, why, why, why?”

One participant -- the only male -- told the others that Hib is a “*type of flu that affects the blood.*”

Some people seemed concerned about why their doctors had never told them about Hib.

What participants reported learning about the Hib vaccine from the information sheet:

Most participants mentioned learning about the side effects and dosing schedule.

Discussion about the information sheet prompted questions or concerns about:

Different brands of the vaccine: There seemed to be some question about whether one brand might be better than another and, if so, why it was not mentioned by name.

Getting more than one vaccine at a time: A few people seemed concerned that getting more than one vaccine at a time would make it difficult to know which may have caused side effects -- or that more than one at a time could even trigger side effects that a vaccine administered individually could not. For example:

“What if you have a reaction? How do they know which vaccine it came from?”

“I want proof that they have put them together [in research] to make sure there was no effect...”

Perception of benefits of Hib vaccine compared to risks:

Participants seemed to accept that the Hib vaccine is important but wanted more information about the benefits and risks of the vaccine. For example:

“I know statistics-wise that there are benefits...I’d still like to see the numbers. I know it’s a better world because of vaccinations...[but want to know, for example] what are the ratios of people getting the disease compared to people getting sick from the vaccine?”

Most important information to provide in the Hib sheet:

Participants said the most important information people need in the Hib sheet is:

The risks of the disease versus the risks of vaccine;
Whether getting the vaccine guarantees that you will *not* get the disease;
How do you get Hib?;
How many people have died from the vaccine?;
How many children have had Hib?; and
How long has the vaccine been out?/Where did they find it?

Response to Varicella Vaccine Information Sheet:

Several participants were surprised and concerned that there is a vaccine for chickenpox. Given that vaccines may have side effects, they said, why would you take a chance to prevent a disease that is “*normal*”? In addition, one participant had heard that “*there is a 50% chance [of getting] chickenpox just from the vaccine.*” This prompted some brief discussion about how vaccines work, with one participant asking, “*All the vaccines give you a small dose of what they’re vaccinating for, right?*”

What participants reported learning about varicella (chickenpox) from the information sheet:

There was very little discussion about what participants thought they had learned about ***chickenpox*** from reading the information sheet. One person said that there was not enough information about the disease -- such as “*where it came from*”, “*how long has it been going?*” and “*how it spreads.*” Two other questions came up:

“Why is gelatin a problem?”

“Why do you need two doses after 13?”

What participants reported learning about the varicella vaccine from the information sheet:

Participants talked more about what else they wanted to know rather than about what they learned. Their questions or interests were about:

The two doses for people over age 13 (this was repeated during this part of the discussion after being raised earlier);

The “*ratios of people who get chickenpox without the vaccine versus those who get it even if they have the vaccine.*”

If the vaccine is likely to give you a “mild” form of *chickenpox*, why isn’t it better to “get the *chickenpox* and make a medication to take it away.” There was fairly strong concern about the risk of getting *chickenpox* from the vaccine. One participant told the group about a television program in which a vaccinated child was used as a “*guinea pig*” and got “*chickenpox so bad he was covered from head to toe.*”

Whether you need a second vaccine after you get the *chickenpox*.

Comparison of benefits of the varicella vaccine versus risks:

No one voiced support for getting the vaccine. They said:

“[This says] you could get it from getting the vaccine so you might as well not get the vaccine. Just take the chance of catching it from school or friends.”

“They should spend more time on things that are fatal than to play around with this. Everybody gets the chickenpox.”

“I don’t really think the chickenpox vaccine is useful.”

Usefulness of vaccine information sheets:

Most participants seemed to like the idea of information sheets about vaccines and thought they would be useful for raising questions with doctors.

Places participants suggested information sheets be available:

Doctor’s offices and clinics;
Schools;
At the hospital when baby is born;
Malls;
Grocery stores;
Pharmacies; and
From visiting nurses who come to your house after baby’s birth.

Awareness of CDC:

Most participants were not familiar with CDC; many had not even heard of it. They were more aware of their local health department and regarded it as a credible source for information about vaccines.

Participants’ additional suggestions about the information sheets:

More use of color;
Make the word “FREE” prominent; and
Add a phone number where people can call for more information.

**CHILDHOOD IMMUNIZATION STUDY
FOCUS GROUP WITH NON-HISPANIC WHITE PARENTS
BALTIMORE, MARYLAND
1:00 PM November 13, 1997**

Moderator: Wendy Child

VACCINE INFORMATION SHEETS REVIEWED BY THIS GROUP:

(1) Hepatitis B and (2) Measles, Mumps, Rubella (MMR)

PARTICIPANTS:

10 parents including 8 mothers and 2 fathers.

SUMMARY OF FINDINGS:

Participants' associations with the word "vaccine":

As in the first group, participants talked about what comes to mind when they hear the word "vaccine." Most participants associated vaccines with positive images about protecting against disease. Most also thought that vaccines for children are mandatory and a few voiced criticism of parents who do not comply. A few people made reference to fear of shots. Word associations or comments included:

"Medicine"

"Protection"

"Vaccine is a good word. Medicine that will prevent you from getting a disease."

"I think it's awful when people don't get their kids vaccinated. I think it's just wrong."

"Squeamish"

"I don't like needles. I'm petrified."

Sources of information about vaccines:

Participants learned about vaccines from doctors, friends, and relatives -- and most people said that mothers and doctors are the most credible sources of information. However, a few people seemed to agree with one participant who noted that some physicians do *not* provide

as much information about vaccines as they could to assure that parents are better informed about benefits and side effects. For example, one person said:

“I have to go to hearsay, my girlfriend, my mother...I think if there was more information for first time moms and dads, it would be a lot easier on us. We wouldn’t be as scared to take our child to the doctor...Some people might feel these shots...are jeopardizing their [child’s] future and their life.”

Other sources mentioned in the group included:

Children’s teachers; and

Television, including public television and *60 Minutes*.

One participant had seen a public television special featuring Johns Hopkins and a story about the hepatitis B vaccine. This participant recalled that the program discussed how the vaccine works and what the side effects are. She thought something should be on television about vaccines once or twice a week.

General response to the hepatitis B Vaccine Information Sheet:

Most people seemed to agree that on a scale of 1-5, with 1 meaning easy to understand, the sheet rated about a 3. Participants said they learned:

Hepatitis B is a serious disease *“not like the common cold”*;
How it spreads;
Why you should get vaccinated; and
Side effects of the vaccine.

However, most people wanted to know more about the disease, where it comes from, and how it can be prevented. As one person put it:

“[Does it come from] improper cooking of food? Outside surroundings?”

Another general reaction included some concern about whether people who cannot read well would understand the information. Two people said:

“A lot of parents out here don’t know how to read. I think it needs to be more simplified in the language they can understand. Maybe showing some pictures.”

“I work with people who say, ‘I’ll get my children to read this to me’...A lot of people don’t know how to read.”

[Note: There was one father in the group who appeared to be unable to read the sheet. He kept looking at other participants to see if they had finished reading and he randomly circled words or phrases in the sheet that participants next to him were marking in

response to the moderator's instructions to note anything that was new or confusing information.]

What participants reported learning about hepatitis B from the information sheet:

Participants generally thought that the information sheet did not contain enough information about the disease. A few people said they had learned that hepatitis B attaches to the liver or that it causes cancer, but most participants wanted to know more. For example:

Information on the virus itself (versus symptoms);
How it is caused;
How it came to the U.S.;
How it attacks your body; and
How to prevent it from occurring. (*"Is there something to eat?"*)

Participants said that the most important information in the sheet was:

The fact that there is a shot to prevent you from getting the disease;

How hepatitis B spreads; and

Who should get the vaccine and when.

Comments and questions included:

"Having sex is a normal thing, but nobody would ever think that you're going to get hepatitis B from it or from sharing a razor or toothbrush."

"How does a mother know whether she has hepatitis B to pass on to the baby? Can she be tested before the baby's birth?"

"If it's so serious, why doesn't everyone get it?"

"If hepatitis B is getting so serious, I think they should have a commercial letting us know we can get checked for it like they had the AIDS virus on television."

"I know we have hepatitis A and I think there's a C one out. If there's a B, why is this the most serious one compared to the other two types?...We're not getting [immunized] for the other hepatitis."

A few participants also seemed to be concerned about whether they could have hepatitis B and not know it because of fatigue or other symptoms mentioned in the information sheet.

What participants reported learning about the hepatitis B vaccine:

Information that participants reported learning about the vaccine from the sheet was mostly about the schedule of when children should get the vaccine, how many doses are involved, and side effects. There was some confusion and question about:

- Why other information sources recommend a different schedule;
- Why the effectiveness of the vaccine is not addressed;
- What to do if you do not know whether you have had the shot.

Perception of benefits of the hepatitis B vaccine compared to risks:

Most people thought that the benefits of preventing hepatitis B outweigh the risks of the vaccine, but there were questions and reservations. People said:

“There’s not very many benefits. There’s more risks.”

“I’d like to see what the effectiveness is of the shot...if they said this shot is only 35% effective, I mean I’d have second thoughts about putting my child through it..because I don’t personally like to pump my child full of drugs...”

“I notice they say 4,000 - 5,000 people die from hepatitis B. What percentage is that [of the people who get it]? I think I’d rather hear percentages.”

“It just doesn’t say a lot like it can help your kids from getting this disease...It should say ‘You need to get this in order to fight off this virus so you don’t die from it.’...[This sounds like] it’s kind of giving you a choice if you should get it...”

What is the most important information to provide in the hepatitis B sheet:

Participants said the following was the most important information people should get from the information sheet:

- Who should get the vaccine and why (especially if adults such as women of childbearing age should get the vaccine in addition to children);
- Risks and side effects of the vaccine;
- Seriousness of the disease;
- Symptoms of the disease;
- Who is most likely to get it (gender and race);
- Warning that “you will get the disease if you do not get the vaccine”; and
- Phone number at CDC to call for information and that the information is available on the Internet.

General response to MMR Vaccine Information Sheet:

Participants thought this information sheet was important because many people think of these diseases as so common that they may not understand the need for the vaccine. Most people also rated this information sheet as slightly easier to understand than the hepatitis B sheet. For example:

“It’s a little easier to understand because it goes right into the disease and tells you the symptoms of it. The other one was...confusing. This is more simplified and the format is good with the paragraphs. The measles part is highlighted...I think that’s what caught my eye. Also, the age of the children [who should get the vaccine] is highlighted.”

General suggestions for improving the sheet included:

- Adding color;
- Make the sheet a 3-fold pamphlet;
- Adding titles for each paragraph;
- Separating information about children from information about adults;
- Using percentages instead of saying “most people who get the vaccine won’t get the disease”; and
- What to do if you do not know whether you have been vaccinated.

What participants reported learning about MMR from the information sheet:

Participants seemed to have some difficulty distinguishing what they learned about the diseases of MMR from what they learned about the vaccine, although, overall, they said this sheet was less confusing than the one about hepatitis B. For the most part, discussion was about some of the things people wanted to know that they had *not* learned. For example:

- Can you can get these diseases if you had them before?
- Are these diseases more serious for adults than children?

What participants reported learning about the MMR vaccine:

Information that stood out for participants about the vaccine included:

Who should and should not get the vaccine; and

The schedule of when and how many doses (although people seemed confused about this)

As with the hepatitis B vaccine information sheet, people wanted to see more numbers or percentages about incidence of both the diseases and side effects. For example:

“It says experts are not sure whether the MMR vaccine can cause permanent brain damage. If it does happen, it is extremely rare. They should show a percentage.”

They also wanted to know how long the vaccine lasts. Comments included:

“Is the [vaccine I had] going to carry me throughout the rest of my life? Should I go back and get another shot for the mumps or measles or whatever other childhood diseases that I got shots for?”

“If you have [the vaccine], will you always be a carrier? Will it go away? Will it come back?”

“...[Have] a special paper to put up on the refrigerator where you can keep an eye out for side effects. It seems like there’s a lot of side effects.”

Places participants suggested information sheets be available:

Doctor’s offices before the appointment so you can read it and prepare questions;
During hospital or clinic visits;
In the hospital right after child’s birth when social worker visits;
Mobile van;
Mail;
Flyers that children bring home from school; and
Library

Awareness of CDC:

A few participants were familiar with CDC and thought this was a good source for information about vaccines. One participant associated CDC with the Poison Control Center.

**CHILDHOOD IMMUNIZATION STUDY
FOCUS GROUPS WITH AFRICAN AMERICANS
WASHINGTON, DC
10:00 AM November 14, 1997**

Moderator: Barbara Hairston

HIB/CHICKENPOX

RESPONDENT PROFILE

There were nine respondents in this group, conducted at 10 AM, in Washington, DC. Eight were female and one was male. One was a grandmother raising her grandchildren. The ages of the children ranged from three months to 13 years.

Respondents seemed to have a limited amount of time to take care of themselves and when they did it typically took the form of reading or relaxing.

ATTITUDES AND PERCEPTIONS OF VACCINES

Objective: To gain insights into respondents' attitudes and perceptions of childhood diseases and vaccines.

Awareness of Vaccines

The term "vaccine" triggered a variety of thoughts within the group. Respondents were generally focused on the process, purpose and the outcome.

<u>Process</u>	<u>Purpose</u>	<u>Outcome</u>
Immunization	school	healthy
shots	flu	get well
germs	infection	disease prevention
doctor	disease	sick
medicine		

Respondents had a limited list of vaccines of which they were aware. They did not include the Hib vaccine about which they had just read. They did include the tuberculosis test, which is not an immunization.

- Flu
- Chickenpox
- Tetanus
- Hepatitis
- Measles and mumps

TB
Rubella

Immunizations – Required Or a Parent's Choice

The respondents overwhelmingly agreed that immunizations are required and are not a choice. This belief was simply a judgment call for some, while others focused on the fact that immunizations are required to attend school.

"It should not be an option. A small amount of prevention can be something so in the long run they will be healthy. The risk of side effects is not even comparable to what would happen if they actually contracted the disease because you chose not to get them immunized. I'd rather be safe than sorry."

"It is not a choice because you cannot get your kids into school if they do not have their vaccinations."

Respondents also agreed that would prefer that immunizations be required because they believed there were many parents who lacked information and might make an uninformed choice or no choice at all.

Safe or Risky

The respondents in this group had children with a variety of medical conditions and as such seemed to have a heightened awareness to side effects. Both asthma and eczema were mentioned as conditions that have been known to be triggered as a result of immunizations. Given that, while respondents agreed that vaccines can be safe, it was also noted that it would be highly dependent on the health of one's child.

Areas of Confusion

Respondents felt that varicella VIS was clearly written and that they generally understood immunizations. Most of the respondents in the group were vocal and seemed empowered when it came to their children's health care. Most had indicated a pattern of reading and researching children's health issues.

Sources of Information about Vaccines and Immunizations

Respondents cited a number of sources of information but almost all started with the doctor's office. In addition, they mentioned:

- Television health feature programs
- Seminars conducted in the hospitals
- Pamphlets available in drug stores
- Health fairs

Alternate Sources of Trusted Information

Trust was not a word respondents would have selected when identifying sources of information. They looked at published information as "giving them something to think about," knowing that they would ask questions about the information until they were satisfied. The questions would be asked of doctors, and others. Respondents did mention that churches and schools distribute this type of information and that they take advantage of the availability of that material.

Respondents were receptive to Web sites for information. Those who were reluctant were those who did not have access to a computer.

Timing

Respondents cited different experiences to explain when they received information. Generally the information was received on the day the shot was given while in the waiting room. The best time to get the information was said to be a couple of weeks prior to the child's scheduled immunization, even during pregnancy.

REACTIONS TO VACCINE INFORMATION SHEETS (VIS)

Objective: To assess reaction to VIS and the degree to which they may shift opinions about diseases and vaccines.

CHICKENPOX VACCINE

Overall Opinion of VIS

Informative was the word respondents used to describe the Varicella VIS. Respondents characterized the sheet as easy to understand.

Most Important Piece of Information

The information presented about side effects was cited as the most important piece of information in the VIS. Though respondents had familiarity with the disease, none felt truly informed. Several agreed that all of the information presented was important.

Favorably Received Information

New and Valuable Pieces of Information

Respondents were consistently surprised at the severity of the disease. It was agreed that knowing the severity actually made them feel afraid.

Green Highlights

Allergic reaction to gelatin

Shingles years later
Sections 4-5
"Small risk of serious harm."
Adverse affect reporting
Injury compensation

Respondents preferred that terms like "small" be explained quantitatively to put the information in perspective.

Unfavorably Received Information

There were no substantive issues raised with the information.

Vaccine

Schedules

Respondents learned valued information about the scheduling of the Chickenpox vaccine. The key information was cited as being "the years when their children should have it and at what age." There was limited previous knowledge, and most did not know the information related to immunizations for ages thirteen years and over.

Side Effects

Some of the side effects were new information. Most did not know about the severity of the possible reactions.

Myths

There were myths associated with Chickenpox which respondents discussed. "Do not eat chicken if you have chickenpox." Respondents agreed that chickenpox has nothing to do with chicken, but believed that a lot of stories have been passed down from older family members.

Disease

New Information

Respondents identified several pieces of new information, particularly the connection between Chickenpox and Shingles.

HAEMOPHILUS INFLUENZAE VACCINE

Overall Opinion of Hib VIS

Respondents were completely engaged while reviewing the Hib VIS because they had so little familiarity with the disease. The reaction to the information was positive. Comments which were more neutral than positive focused on the need for more information.

Respondents agreed that the sheet was easy to understand. When rating the sheet on a scale of 1-5, where 1 was easy to understand and 5 was hard to understand, the sheet was rated 1 most often.

Preferred Additional Information

Respondents wanted more information on what to look for in order to recognize Hib. The question was asked, "What does it look like?" This information was said to be inadequate.

Respondents wanted more quantified information. Numbers and ratios would replace words like "many".

No specific information was said to be missing, however the lack of familiarity with the disease seemed to manifest itself as a lack of confidence in understanding the information presented.

Most Important Piece of Information

Respondents identified the symptoms of the disease as the most important pieces of information on the Hib VIS.

Favorably Received Information

New and Valuable Pieces of Information

Respondents had limited knowledge of Hib. Those who had been aware of Hib felt that what they knew prior to reading the VIS was clearly inadequate when compared to the amount of information provided in the Hib VIS.

Some respondents interpreted the information as saying that the disease was widespread. The phrase "Many more children" will get the disease, suggested that many already had it.

Green Highlights

Many of the severe effects of the disease.

Association with meningitis.

"Covering of the heart..."

Side effects of the immunization

Obtain a Parents Guide to Childhood Immunization from the Health Department

Unfavorably Received Information

Respondents identified several areas of confusion. This was attributable not only to lack of familiarity but also to the believe that there were statements which were unclear.

Red Highlights

The following phrases were perceived to be confusing or negatively received:

Alluding to "health problems", without specifying or suggesting any health problems

Dosage by brands

Visual Appeal of VIS

Respondents' reaction to the visual was neutral. As shown, respondents thought it should be more visually appealing with color and pictures. Pictures of babies were suggested as attention grabbers.

In order to optimize readership, it was recommended that both VIS sheets be included in a pamphlet. The pamphlet should be visually colorful.

Agency Sponsorship

Of the three agencies shown, CDC was the one with the most name recognition, the most positive associations, and the one associated with the least negatives. It was the one name which was said to be able to add credibility to the sheets.

Dept. of Health and Human Resources -- Respondents recognized that the other agencies were part of Health & Human Services. Respondents had negative impressions of this agency because they associate it with welfare payments, Medicaid, and social programs.

There were mixed opinions about the value of the name because of the respondents' association of DHHS with social programs. Showing DHHS was said to detract from the credibility of VIS because "people are angry because of cuts in the program."

National Immunization Program -- There was no awareness of this program. Everyone assumed that it was new.

Centers for Disease Control -- Respondents were most familiar with CDC and reacted most favorably to this agency. A top of mind association was CDC and sexually transmitted diseases. Scientists and doctors also came to mind. The work done on "outrageous" diseases contributed to the positive image held by CDC.

Red Highlights

Baker's yeast, there was no familiarity
"moderate or severe illnesses", needs explanation

Agency Sponsorship

Respondents believed that spelling out the name, Centers for Disease Control, would add the greatest credibility for this VIS. In addition, it was suggested that they name might be even more powerful if it was placed on the front. Neither DHHS nor the National Immunization Program were said to add value.

Dept. of Health and Human Resources -- Some indirect awareness, some government exposure may lead to both positive and negative impressions of this agency. Some saw it as a large, bureaucratic agency while others saw it as an agency trying to help improve the health of the citizens. It triggered thoughts of serious diseases, something that has been really researched. DHHS also made respondents think of the health department as well as the local district government.

National Immunization Program -- There was no awareness of this program.

Centers for Disease Control -- CDC was characterized as the foremost authority on diseases and how to control diseases. Research was also viewed as an important aspect for CDC.

**CHILDHOOD IMMUNIZATION STUDY
FOCUS GROUPS WITH AFRICAN AMERICANS
WASHINGTON, DC
1:00 PM November 14, 1997**

Moderator: Barbara Hairston

HEPATITIS B/MMR

RESPONDENT PROFILE

Eight respondents participated, of which six (6) were females and two (2) were males. They were parents of children ranging in age from three months to seventeen years. Most of the respondents liked to read and were generally knowledgeable about the immunizations discussed.

ATTITUDES AND PERCEPTIONS OF VACCINES

Objective: To gain insights into respondents' attitudes and perceptions of childhood diseases and vaccines.

Awareness of Vaccines

The thoughts triggered by the word "vaccine" tended to be associated with the purpose, process and outcomes related to the shot.

<u>Purpose</u>	<u>Process</u>	<u>Outcome</u>
important	needle	healthy
requirement	medicine	life saver
shots	hurt	thank you
curing	fever	
necessary		
prevention		

Respondents were either had a limited awareness of childhood immunizations or few were top of mind.

Hepatitis
Rubella
Chickenpox (characterized as new and the most recent one)
Measles
Polio drops
TB

Immunizations – Required Or a Parent's Choice

The group was not in total agreement on whether immunization was a requirement or a parent's choice. Most agreed that it is necessary to immunize in order to protect all the children. Isolation was viewed as the only alternative to immunization, albeit unreasonable.

"I agree with the school system, making it mandatory to show shot records before the child is admitted in the school. That also cuts down the spread of various diseases."

"Should only be a choice if you can isolate the child. However children cannot be isolated from each other."

"There is definite interaction, you do not want your child exposed."

When Others Do Not Immunize

Respondents described people who were not conscientious nor health oriented as those who do not immunize.

"Some people are not as conscientious about their children as they should be, and if it were not a requirement a lot of children would not get the vaccinations."

Safe or Risky

It was generally agreed that immunizations are safe. But risk was acknowledged, particularly in the form of "side effects."

In addition, there was a heightened sense of risk when respondents questioned the technique and training of health care personnel.

Areas of Confusion

Respondents agreed that they understood the information provided about immunizations once it was read. However, the issue was the amount of time allowed for reading in order to gain understanding. Respondents did not like receiving information at the same time as the doctor visit. The limited amount of time meant they were unable to read prior to getting to the office. Reading the material there and signing was viewed as unfair.

Source of Information about Vaccines and Immunizations

Respondents seemed to take a more independent approach to identifying sources of information. This was noted because respondents identified sources other than doctors as their sources of information. This

included health magazines, news features, and pre-natal information. Their strategy was to read constantly. The one personal source mentioned was, "ask mother."

Alternate Sources of Trusted Information

Respondents' alternate sources of information tended to include those they *wanted* to trust. There was no blanket trust granted for doctors, or grandparents. Pediatricians, however, were considered an acceptable alternate source.

REACTIONS TO VACCINE INFORMATION SHEETS (VIS)

Objective: To assess reaction to VIS and the degree to which they may shift opinions about diseases and vaccines.

MEASLES, MUMPS & RUBELLA

Overall Opinion of Measles, Mumps and Rubella

The sheet was characterized as being very informative. However, some also believed that the quantity of information was overwhelming. When respondents rated the sheet on a scale of 1-5, on ease of understanding where 1 was easy to understand and 5 was difficult to understand, respondents rated the sheet a 1. Though there was lots of information it was still considered easy to read.

Most Important Piece of Information

Respondents identified the following pieces of information as most important on the Measles, Mumps and Rubella VIS.

Why get vaccinated. This information was empowering because respondents typically rely on the pediatrician to advise them on the required care of their child. This section provided a more in depth understanding of "why" this vaccine was required.

How can I learn more. This section provided a phone number and the availability of a booklet. This section was considered important because it was an additional source of information that could be pursued as needed "to prevent last minute decisions."

Who should get it. This section made the respondents question their own immunization history.

Favorably Received Information

New and Valuable Pieces of Information

Side effects of the vaccine and the effects of the disease itself were the areas of information cited as most valuable. Respondents had the least awareness of the severity of both.

Green Highlights

Injury compensation program

Adults who should get immunized
Mild problems
Effects, deafness or meningitis

Unfavorably Received Information

The information which was unfavorably received tended to be confusing information. Some concepts were presented without explanation or a reason to believe.

Red Highlights

The following phrases were perceived to be confusing or negatively received:

The use of the term "German measles" rather than rubella. Rubella was the more familiar term.

Child bearing age was not clear without a numerical range

Pink eye, this and other symptoms which are not exclusive to measles, mumps or rubella

Allergic reaction to gelatin, needs explanation

Thrombocytopenia

There was no confusion between those issues related to the vaccine versus those related to the disease. Respondents believed that each was clearly identified.

Source of VIS

Doctors' offices and clinics were mentioned as the most expected sources of the VIS. However, respondents also suggested that they might expect to see the VIS at grocery stores and pharmacies.

Respondents believed that there should be prenatal dissemination of the information. This would give parents time to read, understand and question the information in order to make informed decisions.

Visual Appeal of VIS

Respondents continued to believe that the VIS should be colorful. Pictures of babies were also suggested to enhance visual appeal.

HEPATITIS B

Overall Opinion of VIS

This VIS was favorably received but the information included was said to be frightening. This was primarily attributed to the information about the way that the disease was transmitted. Respondents equated being able to contract the disease from someone else's toothbrush with spreading the disease via saliva. The group tended to believe that made hepatitis B easy to spread.

When rating the VIS on a scale of 1-5 on ease of understanding the group rated the sheet a 1, easy to understand.

Most Important Piece of Information

The following pieces of information were cited as the most important pieces of information in the VIS.

The statistics citing the number of people who get hepatitis B, how many go to the hospital and how many die from it were considered important pieces of information.

Dosage was also considered important.

Favorably Received Information

New and Valuable Pieces of Information

Respondents designated the first two sections of the VIS as valuable. Those sections explained why one should be vaccinated and how hepatitis B is spread. With all the sections, statistics were highly credible and added clarity to the fact being presented.

Green Highlights

Why get vaccinated?

How is hepatitis B spread?

Statistics

Infant dosage chart

Injury Compensation Programs

Unfavorably Received Information

The information that was unfavorably received tended to be that with which respondents had no familiarity or that which had insufficient explanation.

**CHILDHOOD IMMUNIZATION STUDY
FOCUS GROUPS CONDUCTED WITH NATIVE AMERICANS
ALBUQUERQUE, NEW MEXICO
6:00 PM November 18, 1997**

Moderator: Scott Carlson

HIB/CHICKENPOX

Background

This group consisted of ten members that were young parents with the exception of one respondent, who was nearly sixty. They represented several area Pueblos and tribal affiliations ranging from San Carlos, San Philippe, Navaho, Pima, Hopi, and Shoshone. They were all females and some were single parents. Through the recruitment process they were screened by education, and income to insure low income and no college education. The group was audio and video taped.

Introduction – Attitudes and Perceptions of Vaccines

When asked what came to mind when they thought of the word Vaccine many of the respondents answered with remarks such as: pain, fear, crying, restraints, and fever. Only two thought of healing and cure.

In general these respondents felt that immunization should be required by the state. They offered reasons such as, protection for their children, prevention from the spread of infection, and it can only help not harm.

In terms of the safety of the vaccinations they seemed to agree that vaccines were safe. Some felt they were safe, but questioned why there was a need for a compensation program.

When asked about what they understood or didn't understand about vaccination they responded in a variety of ways. The responses ranged from not understanding why they are administered at a certain age, to why even though they are administered people can still get infected as with chickenpox. One respondent commented that they didn't understand why they couldn't come up with another method of delivery for vaccinations other than shots.

When questioned about sources of information these respondents referred to experiences of confusion with different doctors and various information they was inconsistent. They offered suggestions of newspaper ads that they could cut out, to a community informational meeting. In general they seemed to suggest that more and varied methods of information availability would benefit them in their community.

REACTION TO HIB INFORMATION SHEET

The first question about the Hib vaccination sheet was what was their overall opinion of the information. The several respondents expressed fear, because of all the potential side effects that were listed. One wondered if there were studies to support what they had printed on the sheets or was it just being used as a scare tactic. Another was concerned by what she had read because as she put it “you worry about it because it says death and stuff.”

These respondents graded the sheet as being moderately easy to understand. Most of them scored it as a two or three on a scale of 1-5, with one being easy and five being hard to understand. One scored it a four because she wanted it to offer more information. Some felt it had too much information while others stated it was easy to read and didn’t have enough information. One respondent commented that while she understood it, she knew there were others who would not.

When offered the opportunity to say what they thought could be added or eliminated from the sheet, one respondent felt that item three could be taken off because it was ambiguous. She wondered how she was suppose to tell her doctor or nurse about adverse reactions if her child had never had it before. Another respondent thought an explanation of how the disease was obtained should proceed the reason why they should get the vaccination. This question generated discussion about concerns as young mothers and how the information is presented to them. Suggestions were made that information be made available at a regular visit before the shots because of the high level of emotion that is experienced during a vaccination visit. Some even suggested using hospital social workers to educate young parents about vaccines. One respondent offered her point of view that many Indian parents couldn’t read and therefore the information would have to be verbalized or it would be of no use. Some of the respondents found the use of charts valuable on the sheet and suggested more of them.

The group seemed to think the information sheet was clear enough, and most of them were able to articulate what they learned from the them. The major theme they seemed to have learned the information sheet was the importance of getting their children vaccinated.

When the question was asked about the clarity of the VIS in terms of getting sick from the disease or getting sick from the vaccine, initially they expressed their belief that it was clear, however throughout the discussion that followed it seemed that it was not clear. Some of the respondents wee not clear whether they could still contract the disease after vaccination. This expression of confusion may be a result of an overall suspicion of health related issues in terms of previous experience and lack of consistent information. Suspicion of substandard heath care plays a large role in the formation of views within the Native American population. When expressed in those terms, that suspicion may have an affect on the expression of views.

REACTION TO CHICKENPOX INFORMATION SHEET

The initial reaction to the Chickenpox information sheet was one of confusion. Several respondents expressed views that they felt the information was inconsistent with what they already knew or had heard from relatives and acquaintances. They wanted more information in many cases because they had so many questions about people getting infected with the chickenpox even after they had been vaccinated. They also posed questions about getting chickenpox more than once.

This sheet was scored as a two or three by this group for reasons that it either had too much information and according to others not enough. Some of the respondents wanted the sheet to answer questions they had about multiply infections, and whether the vaccine worked to completely eradicate the disease after vaccination. Other questions were posed about whether the vaccine only lessened the severity of the infection.

The information on this sheet was evaluated as clear by the group, and most found it useful and informative. When given the opportunity to edit this information sheet, the group seemed to agree that it was clear and they would not eliminate anything.

GENERAL REACTION TO THE INFORMATION SHEETS

The first suggestion that was made on the overall appearance was to print them in red. Several respondents expressed their belief that they are accustomed to pay more attention to things that are written or bordered in red. One respondent noted that “we learn to get acclimated to things in red, so we begin to stop and look.”

When quizzed about the names on the back of the information sheet and asked if they trusted any of the agencies listed one respondent immediately singled out Centers for Disease Control and Prevention as an agency she trusted. When probed she responded, “You always hear about them on the news. When it goes through them, it’s gone through a lot of research cause they always report like on CNN or from the CDC center. When I hear it I listen to it.”

When probed about other agencies like HIS, this group seemed uniformed. They said they have seen health information taped on the walls. They made several remarks that they pay no attention to what IHS has to say. The information and health care received from this agency likely has an impact on the level of suspicion and distrust that several respondents expressed throughout the group discussion.

**CHILDHOOD IMMUNIZATION STUDY
FOCUS GROUPS CONDUCTED WITH NATIVE AMERICANS
ALBUQUERQUE, NEW MEXICO
8:00 PM November 18, 1997**

Moderator: Scott Carlson

MMR /HEPATITIS B

Background

This group consisted of nine members who were all young parents. They are all members of local Pueblos and tribes including Navaho and Hopi. The composition of the group was three men and six women. Through the recruitment process they were all screened by education and income to insure low income and no college education. The group was audio and video taped.

Introduction – Attitudes and Perceptions of Vaccines

When asked what these respondents thought when they heard the word vaccine they responded: shot, ouch, healing, and hospital. In general these respondents seemed to feel that vaccinations are safe although they expressed concern and some worry about the effects on their small children.

This group seemed to have several questions about the safety of vaccinations and as young parents they expressed fear, frustration, and anxiety from the experience. This group commented on the timing of receiving the information. They expressed their frustration about getting the information at the time of the shot because they needed to focus on comforting their children. When probed about alternate sources of information these respondents said they rely on family.

REACTION TO THE MMR INFORMATION SHEET

The overall opinion of this sheet seemed favorable. One respondent said this is the type of information that they should be getting when they take their children in for vaccination. They found new information from reading it and expressed approval for the format.

These respondents gave this VIS high marks for ease of understandability. On a scale of 1-5 with one being easy to understand, these respondents issued marks of one and two. They defined it as specific, self explanatory, and very easy to understand. Those who marked a two didn't understand what thrombocytopenia was. They could determine that it was a blood disorder, but didn't understand the medical terminology.

When asked what was the most important piece of information they gained from reading it, they stated consequences for not getting the vaccination, the importance of adult vaccination, risks, reactions, and the importance of schedules.

One respondent did have some difficulty separating getting sick from the vaccine or getting sick from the disease. He offered several suggestions to aid his misunderstanding. One he offered was to put them on separate sheets. He wanted a separate pamphlet for the side effects so he could check a list after he took his baby home. The only thing the group seemed to think was unnecessary on the information sheet was information about vaccination for college students. They made jokes about the level of intelligence and the need for the information for older people. Their focus was solely on children and infants.

REACTION TO THE HEPATITIS B INFORMATION SHEET

This group called this information scary, but informative. They seemed to focus more on their fear than on the information, and quickly equated the effects of hepatitis B to AIDS. They seemed preoccupied with the transmission of the disease and the difficulty of dealing with the side effects. They called it a “killer disease.”

When these respondents graded this sheet on the scale of 1-5 with one being easy to understand the only scores offered were ones. They said compared to the MMR sheet this one was much easier to understand.

When asked what they thought was the most important piece of information on this fact sheet one of the male respondents quickly answered, “the risks.” Others said “Why get vaccinated, the example of 130,000 people get it each year, the schedule for infants.”

This group expressed fear about what they didn’t know. They seemed quite suspicious of how they could contract the disease and even alleged they thought it could be caught visiting a hospital. They continued to refer to it as “deadly.” That view seemed to dominate their remarks and was apparent throughout the group. They wanted this VIS to be more specific about how they could get hepatitis B. The serious nature of the disease caused this group to ask more questions than they answered at times and they called for clear and concise explanation of anything that was written. They referred back to the MMR sheet on the low platelet count. They want all of that information broken down to layman terms so that they as young people without college education can understand it.

This group did not express any difficulty knowing the difference between when the information was referring to getting sick from the vaccine or getting sick from the disease. This group also defined the hepatitis B information sheet as useful. The only part identified as needing more explanation was number four. One respondent wanted to know what was meant by being at risk. Who was at risk and how to know if you were. Risk was a dominant theme throughout this group.

GENERAL REACTION TO THE INFORMATION SHEETS

This group stated they expected to get this information at hospitals and clinics. One respondent thought that it would be helpful to get this information at several times including when the child was born, before they went to the doctor, and in the doctors waiting room. Another participant said the information should be available early in pregnancy.

The overall appearance of the form was approved of because it is bold. One participant said that red would really make a statement of importance. Another agreed saying it says you need to read this.

When asked about the three agencies listed on the back this group said they trusted them all because they were government agencies and they wouldn't lie, although they didn't have any knowledge about any of them.

Misunderstanding and misinformation influenced much of the discussion in this group. These young American Indian respondents were scared by what they read, but seemed to express more fear about what they didn't know.

**CHILDHOOD IMMUNIZATION STUDY
SPANISH-SPEAKING HISPANIC GROUP
ESCONTRIAS ELEMENTARY SCHOOL, EL PASO, TEXAS
1:00 P.M. November 19, 1997**

Moderator: Maria Ivonne Rivera

HIB/CHICKENPOX

Attitudes and Perceptions of Vaccines

What is the first thought that comes to mind when you hear the word “vaccine?”

Respondent answers were transcribed as being inaudible.

Should vaccines be required by law or should they be a parent’s choice?

Respondent opinions included those who asserted that vaccines should be a parent’s responsibility, those that indicated that they should be required by law, and those who indicated that they should be both required by law and a parent’s responsibility.

Do you understand how vaccines work?

One respondent expressed concern at her understanding that some vaccines are made from eggs, and wondered how they can be given to children who are, say, allergic to eggs. Another respondent expressed an interest in learning more about what is used to make a vaccine, how it is made, how the vaccines are tested, and how people can be assured that the vaccine will prevent an illness.

How did you obtain information about the vaccines that you know about?

One respondent indicated that she obtained most of her information on vaccines from asking her doctor questions regarding vaccines for her children.

Who would you trust to supply you with this information?

Respondent answers included: “A doctor.” “A pediatrician.” “The school.” “The school nurse.” “The clinics.” One respondent did not consider information provided by a friend to be necessarily reliable. Another respondent felt that information provided in the newspaper’s health section was “very good.”

Reactions to Vaccine Information Sheets

Hib Vaccine Information Sheet

How would you rate this sheet on a scale of one to five, with one being “easy to understand” and five being “difficult to read?”

Respondents rated the information sheet as follows:

Rating	1	2	3	4	5	Total
Number of Respondents	1	8	1	0	0	10

What changes would you make to this sheet to make it easier to understand?

Respondent answers included the following:

- Change the name of the vaccine, to make it easier to understand.
- Give more example about the types of allergic reactions that can be produced by the vaccine.
- Explain more about how the illness can be passed from one person to another.

What was the most important piece of information you gained from reading this sheet?

One respondent noted that reading the fact that adults also need to have the vaccine was important for her to learn. Another respondent indicated that the consequences of not having the vaccine seemed most important to her. Another respondent pointed towards the importance of being vaccinated in order to prevent the diseases described was most important.

What did you learn about the immunization schedule?

One respondent indicated that learning when a person should or should not be vaccinated was interesting to her, as was learning about the reactions that can be caused by the vaccine.

What did you learn about the illnesses?

Respondents indicated that they learned about the importance of having the vaccine and the consequences of not having it.

Did you believe the information provided?

Respondents indicated that they generally believed the information, provided it was shared by a responsible professional.

Was the information clear? Would it be clearer if there were numbers that explained complications?

Respondents felt that the information was clear. They generally did not feel that adding numbers or statistics would make the information clearer or more convincing. They noted that using words rather than numbers would help them understand the material better.

What did you learn about the vaccine?

One respondent indicated that she learned about the benefits of the vaccine, especially how the vaccine can at least ameliorate the effect of the contracting the illness.

How do you compare the benefits to the risk of this vaccine?

One respondent noted that she did understand the benefits and risks of the vaccine, and can be more tolerant of her child's reactions to the vaccine because she knows that the vaccine will benefit the child.

How can the information sheet be made even more clear to you?

Several respondents agreed that having the information available to them in Spanish was very helpful.

Sometimes the information refers to getting sick from the disease and sometimes to getting sick from the vaccine (vaccine side effects). Were you ever confused about which one the information was referring to?

Respondents generally agreed that they did not confuse the information the disease with the information on the vaccine.

What could be done to make it more clear?

One respondent suggested changing the name of the vaccine. She also suggested providing more information on illnesses that require a vaccine. Another respondent suggested adding more information on the illnesses themselves, on what the consequences are of not having the vaccine, and who to call for more information.

Did you come across questions that were not answered?

One respondent noted that she did not understand and would recommend more information on how the illness is transmitted. Another respondent recommended explaining more about the illness's symptoms, as compared to, say, a cold.

If there is limited space and you must eliminate something, what would it be?

One respondent recommended eliminating item #3 ("Who should get Hib vaccine and when?") And another recommended eliminating item #7 ("The National Vaccine Injury Compensation Program"). Two respondents recommended keeping items one ("Why get vaccinated?"), four ("Some people would not get Hib vaccine or should wait"), and five ("What are the risks from Hib vaccine?").

Chickenpox Vaccine Information Sheet

How would you rate this sheet on a scale of one to five, with one being "easy to understand" and five being "difficult to read?"

Respondents rated the information sheet as follows:

Rating	1	2	3	4	5	Total
Number of Respondents	2	2	4	0	0	8

What changes would you make to this sheet to make it easier to understand?

One respondent suggested adding information on the amount of time it takes a child to recover from the vaccine and information on the manner in which the illnesses are transmitted. Several respondents agreed that the statement “the majority of people that receive the vaccine do not get the illness” is misleading, as their children invariably contracted the measles despite being vaccinated. One respondent was interested in learning how to distinguish reactions from the vaccine from reactions to something else.

What did you learn about the immunization schedule?

Respondent comments were transcribed as inaudible.

What did you learn about measles symptoms and complications?

One respondent indicated that she did not know the illness could cause herpes.

Was the information clear? Would it be clearer if there were numbers that explained complications?

Respondents agreed that the information was clear and that adding statistics would not necessarily improve the document.

What did you learn about the vaccine?

One participant indicated that she was now able to tell her children what can happen to them if they do not get vaccinated.

How do you compare the benefits to the risk of this vaccine?

Respondents agreed that the benefits of the vaccine are greater than the risks.

How can the information sheet be made even more clear to you?

One respondent suggested expanding the first section (“Why get vaccinated?”) Another recommended eliminating the Internet address, as many of them do now have internet access. Another respondent suggested adding the name and telephone of a doctor or clinic to call for answers to questions.

Sometimes the information refers to getting sick from the disease and sometimes to getting sick from the vaccine (vaccine side effects). Were you ever confused about which one the information was referring to.

Respondents agreed that the information was not confusing to them.

Review of Attitudes and Perceptions

Should vaccines be required by law or should they be a parent's choice?

After the discussion, most respondents agree that the vaccine should be required by law.

Was there anything you did not understand?

One respondent noted that she would still like to know how the vaccine works, what it is made of, and statistics on the incidence of the diseases.

**CHILDHOOD IMMUNIZATION STUDY
SPANISH SPEAKING HISPANIC GROUPS
ARMIJO CENTER, EL PASO, TEXAS
4:00 P.M. November 19, 1997**

Moderator: Maria Ivonne Rivera

MMR/HEPATITIS B

Attitudes and Perceptions of Vaccines

What is the first thought that comes to mind when you hear the word “vaccine?”

Respondent answers were: “pain,” “fever,” “needle,” “reactions,” and “crying.”

Should vaccines be required by law or should they be a parent’s choice?

Most respondents indicated that vaccines should be required by law. One respondent recalled an incident of a six-month-old cancer patient who was administered a vaccine despite her illness and had a severe reaction against it, which led her to think that parents should have some say in whether or not a vaccine is administered.

Do you understand how vaccines work?

Respondents indicated that they understood that vaccines are intended to help children avoid diseases and are administered “for their future...for their benefit.”

How did you obtain information about the vaccines that you know about?

Most respondents indicated that they received information on the vaccines they know about at their clinic or through “papers” they “received” at home.

Who would you trust to supply you with this information?

Respondents replied: “the doctor,” the nurse,” “the clinics,” “The ones that supply the vaccine,” “the school.” One respondent indicated that she could trust the information provided by television, radio, and flyers, but that it was important to have a person, rather than a pamphlet, provide the information, as the spoken word is usually more effective “among Hispanics” than written materials.

Reactions to Vaccine Information Statements

MMR Information Sheet

General Comments

Respondents found the information sheet interesting and found that it contained information they did not know. For example, one respondent indicated that the danger of death from one of these diseases was

something she did not know and impressed her. One respondent indicated that she would have preferred reading the information in English, to understand it better.

How would you rate this sheet on a scale of one to five, with one being “easy to understand” and five being “difficult to read?”

Respondents rated the information sheet as follows:

Rating	1	2	3	4	5	Total
Number of Respondents	3	2	3	0	2	10

What changes would you make to this sheet to make it easier to understand?

Respondent answers included the following:

- Say everything with less words.
- Highlight the dangers children face without the vaccine.
- Have someone read the information to me.
- Attract people to the pamphlet by using different colors.
- Explain what “German measles” are, and how they are different from measles.

What was the most important piece of information you gained from reading this sheet?

One respondent felt that the most important information on the sheet was the information regarding the problems that may arise from not having the vaccine. Another respondent indicated that the fact that death may occur as a result of the illnesses was the most important piece of information, as it scared her, and would scare anyone else reading it.

What on these pages is important to you?

One respondent indicated that the page itself is important because it benefits the children. Another felt that the immunization schedule provided was the most important piece of information provided.

What did you learn about the immunization schedule?

One respondent indicated that she did not know that rubella caused arthritis. Another indicated that she did not know that measles can lead to coughing and mucus. Another indicated that she did not know that when a woman is pregnant and has rubella, the disease can affect the baby. One respondent indicated the information on complications was also important to read.

Did you believe the information provided?

Respondents generally agreed that they believed the information provided.

Was the information clear? Would it be clearer if there were numbers which explained complications?

Respondents agreed that adding numbers would not make the information on complications clearer or more convincing. They pointed out that using words rather than numbers would help them understand the material better.

What did you learn about the vaccine?

Respondents agreed that the information could help them avoid having their children contract measles, mumps, and rubella. Some respondents noted that they used to think that vaccines were simply a good thing to get, not that they helped avoid having their children contract a deadly disease.

How do you compare the benefits to the risk of this vaccine?

One respondent noted that, had her child not received the vaccine, she could now suffer one of these diseases.

How can the information sheet be made even more clear to you?

Several respondents agreed that having the information available to them also in English would help them understand it better.

Sometimes the information refers to getting sick from the disease and sometimes to getting sick from the vaccine (vaccine side effects). Were you ever confused about which one the information was referring to?

Respondents generally agreed that they did not confuse the information on the disease with the information on the vaccine.

What could be done to make it more clear?

Respondents indicated that the document could be improved by clarifying, highlighting, or comparing the risk from not getting the vaccine to the benefits of getting it.

Did you feel the information was useful or not useful? Did the information raise questions that were not answered? What is missing? What would you add? If there is limited space and you must eliminate something, what would it be?

Respondents generally agreed that all of the information was useful. They suggested, however, that an effort should be made to provide all of the information on the sheet using less and simpler words. They indicated the dangers of not having the vaccine and the benefit of having it is information that is absolutely essential to include.

Hepatitis B Vaccine Information Sheet

General Reactions

Respondents expressed interest in learning the relationship of yeast to hepatitis B.

How would you rate this sheet on a scale of one to five, with one being “easy to understand” and five being “difficult to read?”

Respondents rated the information sheet as follows:

Rating	1	2	3	4	5	Total
Number of Respondents	1	4	2	0	0	8

What changes would you make to this sheet to make it easier to understand?

Respondents answered as follows:

- Eliminate the compensation program, as it is not related to the health of my child.
- Explain more about the yeast.
- Make it simpler to read.

What was the most important piece of information you gained from reading this sheet?

Respondents answered that learning the effect of hepatitis B on the liver was important to learn, as was “everything hepatitis B can cause.”

What did you learn about the immunization schedule?

Respondents indicated that they believed the information provided.

Did you believe the information provided?

Respondents referred to information provided on the information sheet.

Was the information clear? Would it be clearer if there were numbers that explained complications?

Respondents did not feel that numbers would necessarily clarify or add to their understanding of the information provided.

What did you learn about the vaccine?

Respondents indicated that they learned how serious and contagious hepatitis B can be, and how the vaccine can help prevent acquiring the disease.

How do you compare the benefits to the risk of this vaccine?

Respondents indicated that the benefits of the vaccine greatly surpass the risk of having complications with vaccine.

How can the information sheet be made even more clear to you?

Respondents generally agreed with one respondent's suggestion that the risks and benefits of the vaccine be juxtaposed to each other on the sheet, in two columns.

As you read through, did the information raise questions that were not answered?

Besides the questions regarding the relationship of yeast to hepatitis B, one respondent suggested adding a statement with respect to who should not receive the vaccine, or the circumstances under which people should not be vaccinated.

What would you add? If there is limited space and you must eliminate something, what would it be?

One respondent suggested adding the picture of a child saying "Mommy, look what would happen to me if you don't take me for a vaccine."

Where should this information be available?

Respondents answered: "where we take the children for the vaccine;" "on the street, flyers, at homes;" at "clinics and schools." Several respondents agreed that having someone teach them the information was more important than having it available for them to read. That is, they preferred "classes" or "lecture conferences at the clinic."

When would it be most helpful for you to get this information?

Some respondents preferred getting it before they went to get the vaccine, to know more about it; others preferred getting the information after receiving the vaccine, in order to take it home with them, read the information, and then throw it away.

Based on the way it looks, how likely would you be to read this? What would it have to look like to make you want to read it?

Respondent comments included "It's boring." "Include children's colors – pink; blue." Show pictures; add illustrations about the topic covered." "Add balloons and children." "A very pretty child would attract readers."

At the end of both sheets, you will see three names: Department of Health and Human Services, National Immunization Program, and Centers for Disease Control and Prevention. What do you know about these agencies? Do you trust the information you get from these agencies/

Respondents indicated that they were only familiar with the Department of Health and Human Services, and that they trusted the information from the agencies.

After reading this information sheet, does it influence your decision to get your children vaccinated?

Respondents generally agreed that the information made them more aware of the importance of vaccines for the health and welfare of their children.

Review of Attitudes and Perceptions

Should vaccines be required by law or should they be a parent's choice?

Most respondents agree that the vaccines should be required by law.

Are vaccines a risk or are they safe?

Most respondents agreed that the benefits of vaccines far outweigh their risk.