The Cognitive Evaluation of Survey Items Related to Vaccine Hesitance and Confidence for Inclusion on a Series of Short Question Sets

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This report presents findings from the evaluation of a set of questions considered for inclusion in a series of short attitudinal questionnaires on hesitance and acceptance of childhood vaccination. The National Center for Immunization and Respiratory Diseases (NCIRD), one of the Centers for Disease Control and Prevention's constituent centers, is tasked with working toward the "prevention of disease, disability, and death through immunization and by control of respiratory and related diseases."[1] As part of this mission, NCIRD tracks vaccine uptake rates and their distributions across the country, and works on messaging campaigns explaining the importance of vaccinations to the American public. To refine their outreach, education, and messaging campaigns, NCIRD conducts ongoing research into the attitudes of parents towards vaccines. Understanding what factors lead some parents to be hesitant towards vaccines is of particular interest to NCIRD.

To further this line of research, NCIRD approached the National Center for Health Statistics' (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) to discuss the design and evaluation of a set of three short questionnaires on childhood vaccine hesitance and acceptance. The final goals for these three question sets was that they:

1. Would explain parents' acceptance of, or hesitance towards, childhood vaccines.
2. Take either 5, 3, or 1 minute for a respondent to complete and be nested within one another (i.e., all of the 1-minute questions are on the 3-minute set; all of the 3-minute questions are on the 5-minute set).
3. Could be inserted into existing or planned CDC, HHS, or nongovernmental health surveys of various modes.
4. Would be valid for parents of children of all age groups—eliminating the need for separate questionnaires for infants, toddlers, children, and teenagers.

To design and evaluate these nested question sets, CCQDER worked with NCIRD to review the existing questionnaires and literature about vaccine hesitance, conducted a series of focus groups to inform the wording and design of an initial set of questions, and finally conducted five iterative rounds of cognitive interviews to both validate the questions and reduce the initial questionnaire down to the final three short sets. This report focuses on the cognitive interviews and their findings, first presenting the methodology used in this analysis. Next, cross-questionnaire findings are discussed, followed by an in-depth, question-by-question analysis. The full initial questionnaire (used in Round 1) is included in Appendix C, while the

[1] https://www.cdc.gov/ncird/index.html

questionnaires used in Rounds 2 through 5 are included in Appendices D, E, F, and G respectively. The final 5-, 3-, and 1-minute question sets are included in Appendix H.

METHODS

Cognitive Interviewing Methodology and the Question Response Process

Cognitive interviewing is a qualitative method whose purpose is to evaluate survey questionnaires, and determine which constructs the questionnaires' items capture (Miller et al 2014). The primary benefit of cognitive interviewing over non-qualitative evaluation methods is that it provides rich, contextual data into how respondents interpret questions, apply their lived experiences to their responses, and formulate responses to survey items based on those interpretations and experiences. Thus, cognitive interviewing data allows researchers and survey designers to understand whether or not a question is capturing the specific social constructs they were attempting to capture, and gives insight into the design changes needed to advance the survey's overall goals. Additionally, the documented findings of cognitive interviews provide data end users with the context needed to more fully understand the quantitative trends that emerge from survey data.

The underlying theory that directs the conduct of cognitive interviews is that of the question response process. Individuals typically interpret survey questions through a four-step process: They first comprehend the underlying construct, then recall the information needed, judge their answer, and finally map their answer onto one of the available response categories, as visualized in Figure 1.

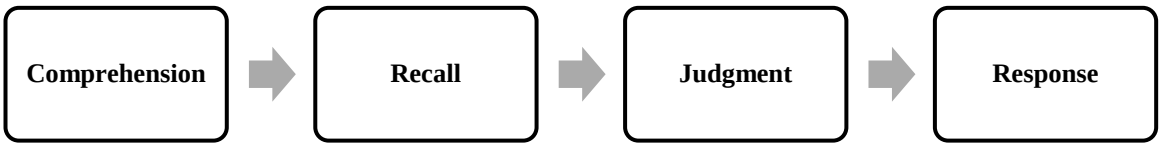


Figure 1. The Basic Question-Response Process Model (Tourangeau, Rips, and Rasinski 2000)

In reality, these four stages of response are not always in the exact order shown in the basic model, and oftentimes respondents either jump around (by, for instance, considering the response categories before judging what they should or should not report on the survey) or repeat steps (if

they decided to try and recall new information after they have judged what they should or should not report on the survey). Additionally, some respondents skip steps in the model, and provide a response to the question that does not necessarily take all of the constructs and information provided in the question text or instructions into account (oftentimes simply basing their answer on a personal characteristic, or perceived personal characteristic, such as health status). Nonetheless, the overall goal of cognitive interviewing is to uncover the specific ways respondents perform each of these four steps.

Cognitive interviews are typically administered as one-on-one, in-depth, semi-structured qualitative interviews. Respondents are first asked survey items, and then probed about their answers and the thought processes behind them. While some cognitive interviewing relies on "think aloud" prompts, which ask respondents to speak through their thought processes as they are answering the survey, this project instead used targeted probing that attempts to determine exactly which constructs the respondents are considering, and how they are judging and formulating their responses. This semi-structured design uncovers not only these constructs, but also question response problems that often are unseen in a survey environment—including interpretive errors and recall inaccuracy. By asking respondents to provide textual verification of their responses, and about the processes by which they formulated their answers, these elusive errors are revealed.

Cognitive interviewing projects use purposive samples, including respondents who have specific characteristics—such as race, education, or occupation—that are assumed to be relevant to the questions being evaluated. When studying questions related to attitudes on childhood vaccines, for instance, the sample would likely consist of parents of various-aged children who express both confidence in and hesitance towards vaccines. Because of the limited sample size, not all demographic or occupational groups will be covered in the sample, and the analysis of cognitive interviewing does not provide generalizable findings in a statistical sense.

As a qualitative method, the analysis of cognitive interviewing data involves the iterative synthesis and reduction of the findings—beginning with a large amount of textual data (the raw transcripts and notes from the interviews themselves), and ending with cognitive schemata and

conclusions that serve the overall purpose of the study. The analysis of cognitive interviewing can be conceptualized in five incremental stages: 1) conducting the interviews, 2) producing interview summaries, 3) comparing data across respondents, 4) comparing data across subgroups of respondents, and 5) drawing conclusions. As each step is completed, data are reduced such that meaningful content is systematically extracted to produce a summary that details a question's performance.

It is the ultimate goal of a cognitive interviewing study to produce this conceptual understanding, and it is through data reduction that this type of understanding is possible. This end analytic product is often best understood as a cognitive schema, examples of which are presented throughout this report and illustrated in a standard format. As shown in a prototypical cognitive schema in Figure 2, the phenomenon or construct under consideration is shown on the left-hand side of the figure, and the various pathways respondents use to understand or judge this phenomenon branch off to the right. Each of the rectangles represents the different patterns of interpretation or judgment, depending on the individual schema, that respondents within the cognitive interviewing sample used when responding to a question. Occasionally, the actual survey answers that each of these patterns of interpretation produced across the sample are also shown, and are represented by ovals on the right-hand side of the figure.

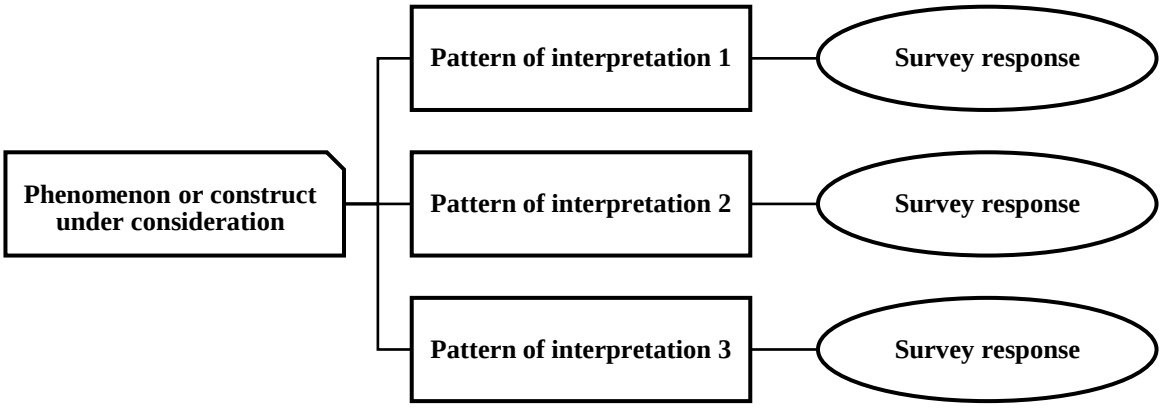


Figure 2. Prototypical Cognitive Schema Used Throughout This Report

Project-specific Methodology

For the evaluation of the childhood vaccine hesitance and acceptance questionnaire, a purposive sample of 50 respondents was recruited to participate in cognitive interviews across five rounds of testing. Interviews took place in Washington, DC (Rounds 1–3 and 5), New Orleans, LA (Round 4), and Pittsburgh and Philadelphia, PA (Round 5). Table 1 shows the sample breakdown by round:

Table 1. Number of Respondents, by Round of Testing

Round	Respondents
1	11
2	9
3	9
4	10
5	11
Total	50

The sample was purposively recruited in an effort to produce a diverse sample across a number of characteristics, including gender, age of child, race, and attitudes towards childhood vaccination. Respondents were recruited through a variety of media, including newspaper and online advertisements. Table 2 shows the genders of the respondents, Table 3 shows the racial composition, and Table 4 shows the distribution of the ages of the respondents' children.

Table 2. Gender of Respondents

Gender	Respondents
Female	32
Male	18
Total	50

Table 3. Race of Respondents

Race	Respondents
American Indian and Alaska Native	3
Asian	4
Black	16
Native Hawaiian and Pacific Islander	1
White	31
Hispanic	2
Note: Total does not equal 50 as respondents were able to select multiple races.	

Table 4. Age of Respondents' Children

Age of Child	Respondents
Less than 1 Year	7
1 Year to 5 Years	17
5 Years to 10 Years	13
Greater than 10 Years	13
Total	50

Most of the interviews conducted in Rounds 1 through 3 took place in NCHS' Questionnaire Design Research Laboratory in Hyattsville, MD. However, a few respondents in these rounds who could only participate outside of business hours or who were unable to gain admittance to the NCHS facility due to citizenship status (as well as all respondents in New Orleans, Pittsburgh, and Philadelphia) were interviewed outside the laboratory. These interviews were held in a public space, such as a coffee shop, which was agreed to by both the interviewer and the respondent. No matter where an interview was conducted, they were limited to 60 minutes in length. Interviews in the laboratory were video recorded, and all others were audio recorded. All respondents received $40 for participating.

The questionnaires in all five rounds were administered by an interviewer. Interviewers in the first four rounds primarily used concurrent probes—wherein respondents were asked follow-up questions immediately after the survey question was administered. In the fifth round, probes were administered retrospectively, which allowed the CCQDER researchers to measure the uninterrupted time it took for a respondent to complete the questionnaire.

Cross-questionnaire Findings

As the overall intent of this project was to design and cognitively validate a series of 5-, 3-, and 1-minute question sets that explained variation in parents' childhood vaccine hesitancy and confidence, the bulk of the analysis presented in this report is found at the question level. These analyses are presented in the next section. However, there were some important cross-questionnaire findings that help explain how the instrument functions overall.

Inter-operability across age groups: One of the key goals of this project was to produce question sets that could work across child age groups. For example, the Parental Attitudes about Childhood Vaccines (PACV) tool was developed (Opel et al 2011a) and validated (Opel et al 2011b) for infants. When the questions were modified for teens (PACV-Modified, Roberts et al 2015), they did not fully predict vaccination outcomes. While the goal of this question set is not to predict outcomes, but rather to establish the components of hesitancy and confidence in childhood vaccines, one imperative is to ensure that the final questions function the same for parents of children of varying ages.

By and large, question interpretation did not vary based on the age of the respondent's child. Any variation in what the respondents believed the questions were asking or on what they based their answers did not appear to be dependent on how old their child was. This is not to say that there was no variation based on child's age—respondents answer survey questions based on their own personal experience, and parents of older children have different experiences than parents of newborns. For instance, many parents of teenagers focused a lot of their response on the HPV vaccine, since their children are of the age when it is administered. In Question 49, parents are asked about their confidence in the safety of childhood vaccines. Parents of newborns largely thought about vaccines such as the Hepatitis B and DTaP shots. On the other hand, parents of toddlers, young children, and teenagers also thought about the influenza, varicella, and HPV vaccines. Nonetheless, nearly all of the parents' interpretations for this question were "in-scope" in that they were using example vaccines to judge the safety of childhood immunizations overall.

The use of the vernacular term "shot" in place of "immunization," "vaccination," or "vaccine": Opel et al (2011) found in a focus group of parents that participants understood

"shots" to refer to vaccines in all forms—and even in cases where parents noted that this term was technically incorrect, they said that they would understand it in a survey environment as a short-hand phrase. Since no large-scale cognitive testing project on vaccine hesitancy questions was conducted prior to this project, there was no evidence that survey respondents would truly understand the vernacular "shots" to mean vaccines in all forms in a survey environment. As such, another goal of this project was to determine whether or not the term "shot" could be used without negatively affecting question interpretation.

The focus groups held at NCHS indicated that parents largely understood the terms "shots," "vaccines," and "inoculations" to mean the same thing. In an effort to further test this, the term "shot" or "shots" was included in a dozen questions in the initial questionnaire (Questions 2, 3, 4, 5, 32, 33, 34, 35, 55, 56, 57, and 65) and then later added to three more items following analysis of the first three rounds of interviews (Questions 39, 48, and 48a). The goal of adding the term throughout the questionnaire was to provide interviewers with ample opportunities to observe how respondents reacted to the more vernacular terms on an official government survey (where the more formal terms of "inoculations" or "vaccinations" might be expected) and to probe whether or not the use of "shot" and its derivatives led to (or reduced) measurement error.

When probed throughout the interviews about how they interpreted the term "shots," respondents equated it with vaccines in general, and not just ones that were specifically injected. The best examples of this come from discussions of the flu and rotavirus vaccines, both of which are (sometimes, in the case of the flu vaccine) administered in a way that does not require a needle stick. Even in these cases, respondents naturally called them shots. For instance, one mother in the third round was asked whether or not she or her daughter had ever received the flu vaccine nasally. She said she had the previous year. When asked what she would call that other than a "shot," she replied "Well, I guess just a medicine? A vaccine, right? But I still called it a flu shot, even though I didn't get a needle, you know?" Another respondent—who was involved in international public health and was highly knowledgeable about vaccines—noted when probed about Question 35 (the overall hesitance scale) that he preferred the term shot, which he understood to mean, "Any vaccine. That includes the flu mist or if they had gotten or received oral polio, which they don't do in the U.S." Similarly, parents of newborns spoke throughout the

interviews about their children's 3- and 6-month shots, which included the rotavirus (which is administered orally). Many parents did not actually appear to recall that their child had received an oral vaccine at these appointments without further probing, but again noted that they just found it easier to call all vaccines shots.

Overall, respondents largely understand the term "shot" to mean all vaccinations—regardless of their actual mode of administration. As such, it should be considered to be a viable term in immunization questions and surveys. In fact, in three cases (Questions 39, 48, and 48a), questions were successfully revised to use "shots" instead of "vaccinations."

Question and Answer Category Formatting and the Use of Good Question Design Principals: One of the difficulties the design team faced when compiling the initial questionnaire was that because of the large number of source surveys, there was no consistency in the amount of introductory text or in the formatting of the answer categories. Because the overall goal of this project was to produce three short sets of questions that could be easily incorporated into any number of ongoing or periodic surveys, an attempt was made during the initial design phase to construct an initial questionnaire with consistently formatted items that were not burdensome on their face. As such, question modifications and *de novo* questions were designed to be as clear as possible with either none or limited introductory text. In an attempt to further reduce cognitive burden, binary options (i.e., Yes/No) were used when possible.

The initial rounds of testing were partially designed to explore whether or not this extensive use of binary options was possible. While the binary option worked in many cases, in some—such as the "confidence" questions (Questions 49 through 59)—cognitive testing revealed that a Yes/No set of answer categories did not fully capture parents' experiences, and therefore added (instead of reduced) cognitive burden. For instance, Question 50 (which asks about confidence in the effectiveness of recommended childhood vaccines) originally asked parents "Are you confident?" and then presented them with a forced Yes/No choice. A number of respondents in Round 1 indicated that they "wanted a middle option" across this set of items and that they felt pressured into answering "Yes" even though they had some slight worries. One father who answered "Yes" to Question 50 said that he is "Fairly confident…my wife argues that it's better

to get the vaccine than chicken pox, but I'm just not completely convinced." In response to these findings, the confidence questions were changed between Rounds 1 and 2, with the Yes/No answer categories replaced with a three-point scale and accompanying question text revisions. This revision appeared to work, as no parents in the later rounds indicated that they felt limited by their options.

"Childhood Vaccinations" versus "Recommended Childhood Vaccines." One of this project's goals was to determine whether or not the terms "childhood vaccines" and "recommended childhood vaccines" captured different sets of inoculations. Previous questionnaires had employed these terms with the hope that "childhood vaccines" would lead respondents to consider the full set of vaccines given to children and that the term "recommended childhood vaccines" would lead the respondent to think only of the vaccines their doctor had recommended to date. The initial questionnaire used in Round 1 of cognitive testing included items that used both of these terms in an effort to examine whether this distinction emerged across the respondents' interpretations.

This distinction did not appear to effectively frame the questions; regardless of which term was used, most respondents focused on personally salient vaccines. Oftentimes this was either "new" vaccines (i.e., HPV or chicken pox vaccines) or the flu shot. For instance, one mother explained that when answering Question 49 ("How confident are you that all recommended childhood vaccines are safe for your child?", which she answered "Not at all confident"), she was thinking specifically about the flu shot: "The flu shot is not safe for anyone. It's not a safe vaccine—too many side effects like fever, chills, achy body, and vomiting…I don't know anyone who had the flu shot who does not get the flu. They're ineffective…I question their effectiveness." However, upon further probing to this question and to other questions, this respondent noted that her child was fully vaccinated and that she did not have the same issues with childhood vaccines overall.

However, some respondents did indeed focus on all recommended vaccines or the full set of childhood vaccines when asked. For instance, when answering the same question on the safety of recommended childhood vaccines, one father who answered "Somewhat confident" explained that he could not be sure that each and every vaccine was 100% safe. However, he answered a

later question about the safety of the HPV vaccine specifically (Question 52) “Very confident.” When asked about the divergent answers, this respondent explained that he had studied up on the HPV vaccine specifically and had not seen any indication that it was not safe, but that again, he could not be fully confident for all childhood vaccines because he had not done the same amount of research on the full set. Nonetheless, the number of parents in the cognitive interviewing sample who focused only on salient vaccines was much greater than the number who focused on the full set of vaccines, so this framing mechanism does not appear to be a viable design mechanism.

Question-by-Question Analysis

This section presents the question-by-question analysis of the entire initial questionnaire. Questions are presented in the order they were originally administered in Round 1. Revisions to the questions are provided and labeled with the rounds in which they were administered. Each question's write-up includes two subsections. First, information on the question's design and conceptual background is provided—including any source survey questionnaires from which it was adapted, the universe that received the question, and whether or not it was included in any of the final three (1-, 3-, and 5-minute) questionnaires. Second, the cognitive findings from the narrative data are presented, with a focus on the constructs that the item captures and process by which respondents judged their answers.

Q1: Has your child received all, some, or none of the recommended vaccines to date?

1. **All**
2. **Some**
3. **None**

Question Design and Background

This question was asked of all respondents across all five rounds. The intent of this question was to capture information about the vaccine habits of the parents, and functioned in this project as a proxy for the more detailed information that the surveys on which the short sets will be included already capture. As such, it is not recommended for inclusion in any of the three short sets.

Similar questions included in the HealthStyles Survey[2] and the National Poll of Parents[3] informed the design of this item. This question was administered to all respondents in Rounds 1 through 5.

Findings

Respondents largely understood this question as asking whether or not their child had received all of the shots or vaccines they had been told they were supposed to get. Variation emerged

[2] Question VYPLAN
[3] Question 1

across how the respondents interpreted the phrase “recommended vaccines” and whether they judged their answer based on their intent or on actual behaviors.

Interpretation of “Recommended Vaccines”: Four patterns of interpretation of the phrase “recommended vaccines” emerged:

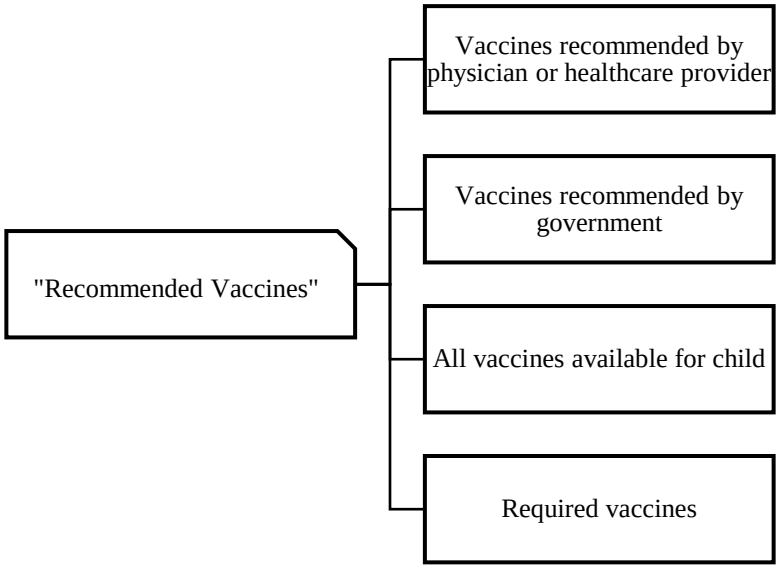


Figure 3. Patterns of Interpretation of the phrase "Recommended Vaccines" in Question 1

Most parents understood this question to be asking about the vaccines their child’s pediatrician (or primary care provider) suggested. For instance, one respondent who answered “All” explained that he was thinking about “all the vaccines the doctor recommended,” but when probed further noted that he did not know the full list of vaccines—but instead basically relied on whatever the doctor told him. Another respondent, who answered “None” also said she was thinking about her doctor’s suggestions, saying “he [the pediatrician] has recommended a bunch, but I’ve said no to all of them.”

Other respondents said that they considered “recommended vaccines” to be those suggested by a government or a governmental agency, such as the CDC schedule in the United States[4]. For instance, one respondent who answered “All” explained what she was thinking by noting, “I think of the CDC chart. It’s the only recommended chart that I’m aware of.” Similarly, a respondent whose child was born in Canada explained that he knew his daughter was vaccinated

[4] https://www.cdc.gov/vaccines/schedules/index.html

according to the "Canadian schedule…which is more spread out than the one here [in the United States]," but he could not say which specific vaccines she had been given. Other respondents explained that they assumed that the CDC schedule and their pediatrician's schedule were one-and-the-same, reasoning that the CDC must give a recommended schedule to American doctors. (In fact, the American Academy of Pediatricians does recommend that its members follow the CDC schedule.[5])

A few respondents took a very broad view of the phrase "recommended vaccines" and noted that they were thinking of all of the vaccines that a child the same age as theirs could possibly receive. For instance, one parent who answered "All" explained that "It includes the flu [shot]. Basically, it's all vaccines that would be normally accepted for a child…the only one they haven't gotten yet is Gardasil." (This child was aged 10 at the time of the interview, and the HPV vaccine is generally suggested at age 11.)

Finally, some other respondents understood "recommended vaccines" to mean "required vaccines." These parents were thinking about the specific vaccines their children needed to have to participate in activities such as sports, attend school, or even continue to go to their pediatrician's office. One participant in Louisiana who answered "All" explained his thinking by saying, "The ones the doctor says you have to get…the law says you have to get the vaccines [for your child], and if you don't, you'll go to jail."

Judgment: Respondents judged their response to this question in one of two ways: by considering either their actual behavior or their intent with regards to childhood vaccinations. Most respondents reported about their actual behavior, treating this question as a factual one. For example, one respondent who reported "Some" explained that while it was her intent to get her son all of his vaccines, the family's health insurance had lapsed for a few months, and she was still working on "catching him up." Because her son had missed a few shots, she felt like "Some" was the best answer. On the other hand, a small number of respondents understood the question to be more attitudinal, and reported on their intent (and not on their behavior). For example, one mother who answered "All" went on to say, "Well, we're a bit behind," explaining that they had

[5] https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/immunizations/Pages/Immunization-Schedule.aspx

to miss a few appointments with her child's pediatrician for various reasons. However, this respondent believed that "All" was the best answer, because she believed in getting her child vaccinated and planned on catching him up as soon as she could.

Q2: During the past 12 months, has your child received a flu shot? A flu shot is usually given in the Fall and protects against influenza for the flu season.

1. **Yes**
2. **No**

Question Design and Background

During the focus groups, participants appeared to group vaccines into three categories: 1) "standard" or "old" vaccines (such as the Measles, Mumps, and Rubella vaccine) that they had heard a lot about or had received themselves as children, 2) "new" vaccines such as the HPV and chickenpox vaccines that had come on the market after their childhood, and 3) the flu shot. While parents understood that the flu shot (or spray) was a vaccine, most thought about it separately since it was something that they had to get (or get for their children) annually instead of once or only rarely (such as the tetanus booster). Because of this conceptual separation that emerged out of the focus groups, the initial design of the vaccine hesitance questionnaire included questions such as Question 2 that asked about the flu shot apart from other vaccines.

A similar question is asked on the National Internet Flu Survey (NIFS)[6]. This question was administered to all respondents in Rounds 1 through 4.

Findings

Interpretation of "Flu shot": As noted above in the overall findings, almost all of the respondents understood this question as asking about whether or not their child had received a flu vaccine in any form. One parent (who answered "Yes") explained that he was only thinking about the injection of the vaccine, as he did not realize that it could come in any form except for a shot. Aside from this respondent, however, the rest of the sample understood that the question was about the vaccine in general, and not simply the "shot" administration. One respondent who

[6] Question 1

answered "Yes" explicitly noted this, saying, "[Her child] got a flu vaccine…regardless of how it was administered. 'Flu shot' is a colloquialism."

Judgment: Similar to what was observed in Q1 (which asked about all recommended childhood vaccines), respondents judged their responses based on two criteria. Some respondents thought about the exact time their child had received the shot, while most simply based their response on whether they considered this a typical behavior. For example, one mother who answered "Yes" noted that her seven-year-old had been given the vaccine at his annual checkup in November. This parent recalled that she was given the option of her son getting the mist or the shot, and she picked the shot. However, most respondents simply answered based on their typical behavior, and did not think of specific instances where their child did or did not get the vaccine. For instance, one parent who answered "No" explained that the family stopped getting flu shots a few years ago, but did not try to remember the specific instances in the past year where his child's pediatrician offered the shot. Likewise, another parent answered "Yes" saying that her six-year-old "…gets one every year. The doctor just gives it to him in the Fall." This latter pattern of judgment may lead to response error. For instance, one respondent who answered "Yes" explained upon in-depth probing that he was not responsible for taking his daughter to her doctors' appointments, but rather his ex-wife was. When asked how he could be sure that his daughter had received the shot in the past 12 months, this respondent admitted that he was just assuming, since his wife tends to "be on top" of healthcare appointments and that in reality, his answer should have been "Don't know."

Q3: How often does your child receive the annual influenza, or flu, shot?

1. **Every year**
2. **Some years**
3. **Never**

Question Design and Background

Because the flu shot is offered annually, Question 3 was included in the initial question set to obtain information about how frequently the respondents accepted or rejected the flu shot for their children. The reasoning here was that respondents who always or sometimes rejected the flu

shot for their children would be more hesitant towards vaccines than parents who never rejected the vaccine.

No similar question was included on any of the source questionnaires, and this question was designed *de novo* for this project. This question was administered to all respondents in Rounds 1 through 4.

Findings

Respondents carried their interpretations of the previous question (about getting a flu "shot" in the past 12 months) into this question about frequency. They universally understood this question to be asking about how often their child received a flu vaccination. All of the respondents who answered "Every year" to this question answered the previous one "Yes;" while all of the respondents who answered "Never" to this question responded "No" to Question 2.

Q4: Has your child received an HPV shot?

1. **Yes**
2. **No**

Question Design and Background

As noted above in the background on Question 2, the focus group participants tended to group vaccines into three sets—older, "standard" vaccines; "new" vaccines; and the annual flu shot. This question was designed to obtain information about the second group, in which respondents tended to lump the HPV, chicken pox, and shingles vaccines.

In the first round, this question was administered to all respondents. However, parents of young children were confused by this question, as they had not been given the option of the vaccine yet by their doctors (according to the CDC schedule, the HPV vaccine is typically administered at age 13). This confusion led to a number of false positives, with respondents either reporting on what they intended to do when their child turned 13 or with respondents reporting about other vaccines that they confused with the HPV one. After consulting with NCIRD, the decision was

made to only administer this question to parents answering about children 10 and older, and to skip parents of younger children out of both this question and its follow-up (Question 5).

This question is similar to one administered on the NIS-Teen Survey[7]. It was administered to all respondents in Round 1, and to respondents answering about children aged 10 and older in Rounds 2 through 4.

Findings

Comprehension: While most respondents understood that this question was asking about whether or not their child had already received an HPV vaccine, the phrase "HPV shot" caused some confusion. Across the five rounds, six respondents answered this question "Don't know" and others who provided either a "Yes" or "No" answer admitted to being unsure. This confusion appeared to stem largely from the fact that the HPV vaccine is colloquially known by its brand name ("Gardasil"). Furthermore, not all respondents knew that Gardasil prevented HPV, instead relating the vaccine directly to one of the major complications caused by HPV, cervical cancer. For example, one respondent who answered "Don't know" immediately reacted to the question by saying, "I don't know what that is." Upon retrospective probing, this parent noted that she had heard of Gardasil, but did not know what it was for, nor whether or not his daughter had been given it by a doctor. Another respondent answered "No," but noted that she wasn't sure what the HPV vaccine was. Again, upon retrospective probing, this respondent revealed that her son had been administered Gardasil earlier in the year.

Judgment: Unlike what was observed above for the questions about all recommended childhood vaccines (Question 1) and the flu shot (Question 2), all respondents based their answers to this question on their actual behavior and not based on their intent. For instance, one of the respondents who had difficulty with the phrase "HPV shot" answered "No," explaining that she had never heard her child's doctor mention that. However, upon probing, she noted that she did remember her child's pediatrician administering Gardasil. None of the respondents who answered "Yes" to Question 4 were reporting based on their intent to get their child the HPV vaccine.

[7] Question 1

Q5: Are you planning for your child to receive the HPV shot in the future?

1. **Yes**
2. **No**

Question Design and Background

Because the HPV vaccine is offered across a wide period on the CDC schedule (between 9 and 18, including for high-risk and "catch-up" groups), and because the focus groups and conversations with subject matter experts at NCIRD suggested that HPV was among the more resisted vaccines, Question 5 was included to explicitly ask the respondent about their intent. The goal of this question was that by gathering information about their intent to provide their child with a commonly resisted vaccine, this would function as an indicator of a parent's vaccine hesitance.

Respondents who did not answer "Yes" to the previous question (Question 4) about whether or not their child had already received an HPV shot received this question. As noted above in the description of Question 4, after the first round of cognitive testing, only parents answering about children aged 10 and over were administered Questions 4 and 5.

No similar question was included on any of the source questionnaires, and this question was designed *de novo* for this project. This question was administered in Rounds 2 through 4.

Findings

Respondents universally understood this question to be asking about their current intent vis-à-vis the HPV vaccine. This question was not probed extensively, and detailed findings are not available.

Q5a:

[VERSION 1 – Round 2]

Is your child administered vaccine following your pediatrician's recommended schedule, the CDC's recommended schedule, or some other schedule, such as the Sears Schedule?

1. **Pediatrician's recommended schedule**
2. **CDC's recommended schedule**
3. **Some other schedule**

[VERSION 2 – Round 3]

Is your child administered vaccine following your pediatrician's recommended schedule, the CDC's recommended schedule, or some other schedule, such as the Sears Schedule?

1. **CDC's recommended schedule**
2. **Some other schedule**

[VERSION 3 – Rounds 4 and 5]

Is your child administered vaccine following a standard schedule, or some other schedule, such as the Sears Schedule?

1. **Standard schedule**
2. **Some other schedule**

Question Design and Background

Following the analysis of the first round of cognitive interviews, it became clear that most parents talked about the "list" or "schedule" of vaccines they followed (either on their doctor's advice or not) when planning and approving their child's vaccines. However, no question in the Round 1 questionnaire explicitly asked about the schedule the respondents used. It was particularly clear that the choice of a schedule was important for vaccine-hesitant parents—in Round 1, two parents noted that they had told their child's pediatrician that they had decided to follow the "Sears Schedule," which is an alternative to the CDC-recommended schedule that spreads out the administration of vaccines (Sears 2007). These parents explained that they chose this alternative schedule because they did not believe that their child should receive multiple inoculations per doctor's visit. Question 5a was therefore designed to capture the schedule that the parents use for their child's vaccinations—specifically, whether or not the parent uses an alternative schedule that is different than the CDC-approved one.

No similar questions appear on any of the in-use questionnaires that CCQDER reviewed, and this question was designed *de novo* for this project. Three versions of this question were tested

across Rounds 2 through 5. The first version was used in Round 2, and included three answer categories ("Pediatrician's recommended," "CDC's recommended", and "Some other schedule"). The "Pediatrician's recommended schedule" category overlapped in some respondents' minds with *both* the CDC's recommended and the alternative schedule categories, and therefore caused response error. The second version of the question reduced the list to two answer categories and eliminated the "Pediatrician's recommend schedule" option. However, testing outside of the Washington, DC areas (in New Orleans, LA) revealed that the term "CDC's recommended schedule" was not well-understood. Re-analysis of the focus group and first three rounds of cognitive interviewing's data indicated that the vernacular term "standard schedule" may provide an appropriate answer category that indicates the opposite of "some other schedule" (which testing across Rounds 2 and 3 indicated captured the idea of an alternative or non-official schedule). Version Three, used in Rounds 4 and 5, used the two answer categories "Standard schedule" and "Some other schedule." This version appeared to reliably capture the intended constructs.

Question 5a (Version 3) is included in all three (1-, 3-, and 5-minute) final short sets. It was administered to all respondents in Rounds 1 through 5.

Findings

Overall Comprehension: Respondents universally understood all three versions of Question 5a to be asking about the list and timing of the vaccines their children had already received and were to receive in the future.

Specific Interpretation of Version One: Version One of Question 5a was used in the Round 2 cognitive interviews. This version was structured as a forced choice question with three answer categories—pediatrician's recommended schedule, CDC's recommended schedule, and some other schedule. Interpretations of these three answer categories overlapped, as shown in Figure 4, and resulted in response error. In the schema depicted below, the answers each pattern of interpretation (the rectangles) produced are shown in the ovals.

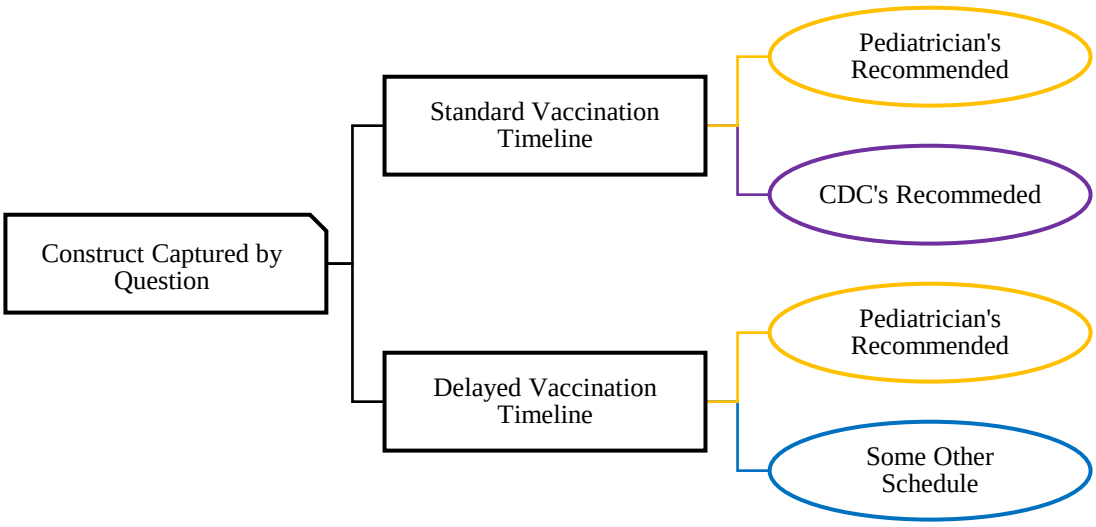


Figure 4. Patterns of Interpretation, and Associated Survey Answers, for Question 5a

Two patterns of interpretation emerged from respondents' understanding of Version 1 of Q5a. Respondents either thought about standard vaccination timelines that were approved by some governmental or nongovernmental authority—such as the CDC or a medical association—or about schedules that delayed when certain shots were administered in order to give children's bodies more time to adjust to the inoculations. While the intent of the question was to capture these two constructs, unfortunately, the respondents did not judge their responses consistently. Respondents who answered "Some other schedule" were all thinking about a delayed schedule, and respondents who answered "CDC's recommended schedule" were all thinking about a standard schedule.

However, those respondents who used the "Pediatrician's recommended schedule" answer category were split between these two patterns of interpretation. For example, one respondent who answered "Pediatrician's recommended…" explained her response by saying, "We just follow whatever the doctor says. I guess we agreed to it, but it's just what [her son's] doctor recommended." Upon further probing, this parent said that she "assumes" it's the same as the CDC schedule, noting "I'm sure [the doctor] follows what the CDC says to do." However, another respondent who answered "Pediatrician's recommended…" explained that her daughter's doctor offered both a standard and a delayed schedule, and that she and her husband decided that they wanted their daughter to have fewer shots at one time so they chose the delayed

one. When asked if she thought it was different from the CDC schedule, this respondent said, "I'm not sure. He certainly never presented it as the CDC schedule."

Q6: In general, how would you describe your child's health?

1. **Excellent**
2. **Very Good**
3. **Good**
4. **Fair**
5. **Poor**

Question Design and Background

Versions of this question are used across a number of health surveys in the United States, including the National Health Interview Survey (NHIS)[8] and the National Health and Nutrition Examination Survey (NHANES)[9]. As explained in more detail in Appendix A, the initial design of the questionnaire used in Round 1 was based on the Anderson Model of Health Care Utilization (1995). A component of this model is the predisposing health characteristics of the child. As the general health question has been previously shown to be highly correlated to various aspects of an individual's health, this proxy-report version was included in an attempt to obtain information about the child's overall health.

This question was administered to all respondents in Rounds 1 through 4.

Findings

Comprehension: Previous cognitive evaluations of this question in its self-report form show that adult respondents consider a wide variety of aspects of health when answering this question—ranging from diet and exercise to healthcare utilization and illnesses (see Scanlon 2017, p5). However, when adult respondents serve as proxy respondents for their children, this range is dramatically reduced.

[8] Question PHSTAT
[9] Question HSD010

These four patterns were not evenly distributed across the four rounds' worth of respondents who received and answered this question, with nearly all of them (77% of the sample) focused exclusively on their children's propensity for illness or chronic conditions. For example, one parent who answered "Excellent" explained that she was thinking about how her son had "No issues other than the usual stuff: 'Oh my nose is running' or 'Oh, I have a cold.' But nothing major, nothing hospital-worthy." Similarly, another parent who answered "Very Good" noted that her daughter "…is never sick, but she always claims to be…she's had two surgeries, which is a lot for an 11-year-old." A few parents were thinking about their child's diet or exercise habits instead of their illnesses or chronic conditions. For instance, one parent who answered "Very Good" explained that his son had a poor diet overall and "eats inconsistently," while another parent who answered "Excellent" noted that her son "is always running around and is very active."

Judgment: Three patterns of judgment emerged from how the respondents decided upon their answers to the general health question. Most respondents framed their decisions in terms of "how many" illnesses or how often their child was sick. For example, one parent who answered "Excellent" said that she answered that way because,

> He's always been healthy. Other than his well-checks he's hardly ever had to go to the doctor. And in his 8 years he's only had 2 prescriptions ever. One for an ear infection and one for strep throat. He plays a lot of sports and he's just active and healthy.

In a similar vein, another respondent explained that he answered "Very Good" instead of "Excellent" because his child had a couple of health conditions and habits, and he could not therefore say he's the best: "He's not athletic or flexible, and really not that active."

Other respondents judged their answer based on what their child's level of health was as compared to average. For instance, one respondent who answered "Excellent" explained that her daughter's experiences were normal: "Flu, cold. But nothing out of the ordinary." Another parent who answered "Very Good" explained that she didn't say "Excellent" because her child was in a lower-than desired percentile for weight and height.

Finally, a couple of respondents all explained that they did not answer "Excellent" because their child wasn't perfect—so in other words, the standard upon which they were judging their response was not "average" or "normal" like the respondents above, but rather perfection. For example, one parent who answered "Good" said that she did not answer "Excellent" because that would mean that her child never got sick, and he does occasionally (she furthermore believed that there was no difference between "Good" and "Very Good" on the scale). Another parent who answered "Very Good" noted that his daughter is "a healthy two-year-old girl, but no one's perfect."

Q7: Does your child currently need or use medicine prescribed by a doctor, other than vitamins?

1. Yes
2. No

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was only administered in Round 1.

Findings

This question was not systematically probed, and no findings are available.

Q8: Is your child covered by some form of health insurance or other healthcare coverage?

1. **Yes**
2. **No**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was only administered in Round 1.

Findings

All respondents understood this question to be asking about whether or not their children were on a health insurance plan. Furthermore, all 11 respondents in Round 1 answered "Yes" to this question. For example, when asked what she was thinking about when answering Question 8, one mother answered, "He's [the child] been covered since January. Before that, there was a 9-month gap because of a snafu." This respondent said that she would have answered "No" during this lapse, and explained that it was related to the fact that she and her husband had declined employer-based insurance because they believed that their Medicaid would last another year, but it did not and they had to pay out-of-pocket for about 9 months.

Q9: In the past 12 months, did you and your family have problems paying, or were unable to pay, for any of your child's medical bills?

1. **Yes**
2. **No**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get

information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was administered to all respondents in Rounds 1 through 4.

Findings

Across the four rounds, all but two respondents answered "No" to this question; and all respondents interpreted it as asking whether or not the money they had to spend on medical bills put themselves or their family under financial pressure. As noted above in Question 8, all respondents in the sample indicated that their child was covered by health insurance at the time of the interview. (For comparison purposes, the National Health Interview Survey indicated that 5.1% of the population below the age of 18 were uninsured in 2016[10].) The two respondents who answered the question "Yes" indicated that their child had extra medical expenses that were not covered under their plan. For example, one of these parents explained that his insurance did not fully cover his child's broken arm, and that the family is still paying off approximately $2,000 worth of expenses.

Q10: In the past 12 months, have you been frustrated in your efforts to obtain health care services for your child?

1. Yes
2. No

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was only administered in Round 1.

[10] See https://www.cdc.gov/nchs/data/factsheets/factsheet_health_insurance.htm

Findings

All but one of the respondents in Round 1 interpreted this question to be asking whether or not they had difficulty obtaining services from their child's doctor or doctors, or difficulty getting prescriptions. All of these respondents answered the question "No." However, the one respondent who answered this question "Yes" instead thought about the frustration they had with the health insurance company (as opposed to problems with their healthcare provider). This respondent reported that their child's health insurance lapsed for a few months because of what she called "bad information," and she found the situation to be frustrating. However, upon further probing, this mother indicated that her child did not need care at all during this period of un-insurance, and she did not have to pay anything extra out-of-pocket.

Q11: Is there a place that your child usually goes when [he/she] is sick or you need advice about [his/her] health?

1. **Yes**
2. **No**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was administered to all respondents in Rounds 1 through 4.

Findings

There was some variation in respondents' interpretation of this question based on their experiences. Respondents with children who go to their doctors' offices regularly (either because of illness or for checkups) uniformly understood the question to be asking about the place where their children typically received this care. For instance, when asked what she was thinking about when she answered this question, one parent (who answered "Yes") simply said, "Yeah, the doctor's office." Likewise, another parent who answered "Yes" explained that even though the

one time his child was seriously ill they used an urgent care clinic, he was thinking about his daughter's pediatrician to be "our primary source of information" and care. On the other hand, one respondent who answered "No" explained that he does not have a single place that he tends to take his daughter. While his daughter has a pediatrician of record, he always likes to consult other doctors to get second or third opinions when making healthcare decisions.

Parents whose children did not regularly need care or visit their pediatricians, however, used two separate interpretations when answering this question. Some parents (all of whom answered "Yes") understood this question as a hypothetical and answered based on what they would do *if* their child needed care or they needed advice. These parents all reported that they were thinking about their child's pediatrician—even though they did not necessarily use his or her services. Other parents, however, did not engage in this hypothetical and answered the question "No," explaining that their child did not have a place that he or she "usually" went. For example, one respondent who answered "No" explained that "[child] just doesn't get sick" and therefore does not need to go to a doctor enough to have a "usual" behavior.

Q12: What kind of place is it—a clinic, doctor's office, emergency room, or some other place?

1. **Clinic or health center**
2. **Doctor's office**
3. **Hospital emergency room**
4. **Hospital outpatient department**
5. **Some other place**
6. **Does not go to one place most often**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was to the 10 respondents in Round 1 who answered "Yes" to Question 11. This question was administered in Round 1 only.

Findings

Most respondents who received this question answered "Doctor's office" and simply noted that they were talking about their child's pediatrician. This question was not probed systematically, however, and no further findings are available.

Q13: Is this the same place that your child usually goes when [he/she] needs routine or preventive care such as a physical exam or well-child check-up?

1. **Yes**
2. **No**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was administered to respondents in Rounds 1 through 4.

Findings

This question was not systematically probed, and no findings are available.

Q14: Is this the same place that you go when seeking advice about your child's vaccinations?

1. **Yes**
2. **No**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was administered to respondents in Rounds 1 through 4.

Findings

Of the 37 respondents who were administered this question, 35 answered "Yes," while only two answered "No." All of these respondents, however, understood the question to be asking whether or not the place they answered about in Question 11 was also the place they received advice or care. For example, one respondent who answered "No" explained that he felt like his child's pediatrician was not his primary source of vaccine advice, and that he trusted his friend's opinions just as much or more. He related that he likes to discuss medical options with a wide range of people, and in general "I keep an open mind."

Q15: During the past 12 months, was there any time when your child needed health care, but it was delayed or not received?

1. **Yes**
2. **No**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was administered to respondents in Rounds 1 through 4.

Findings

Nearly all respondents answered this question "No," with only four respondents answering "Yes" across the four rounds. Respondents universally understood this question to be asking about whether their child's care had been delayed in the past year, for any reason. For instance, one respondent who answered "Yes" noted that her pediatrician's office did not have any openings the day she wanted to go, and therefore her daughter had to wait a few days before seeing her doctor. Another parent was thinking about financial reasons for a delay, when she

explained her "Yes" answer by noting that her child's insurance had lapsed and his annual check-up had to be delayed for a few months.

Q16: What kind of place does your child usually go to when [he/she] needs routine or preventative care, such as a physical exam or well-child check-up?

1. **Does not get preventative care anywhere**
2. **Clinic or health center**
3. **Doctor's office**
4. **Hospital emergency room**
5. **Hospital outpatient department**
6. **Some other place**
7. **Does not go to one place most often**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was administered in Rounds 1 through 4 to respondents who answered "No" to Question 13.

Findings

Only one respondent skipped into this question by answering "No" to Question 13, and no findings are available.

Q17: How long have you known your child's doctor?

1. **[OPEN]**

Question Design and Background

During the focus groups, one point that participants continually returned to when discussing how much they did or did not trust their children's doctors was how long they had known (and correspondingly used) that doctor. For instance, one parent who mainly took her daughter to a

local pediatric clinic at a hospital for medical care (and therefore did not have a single, permanent primary care pediatrician) said, “I don’t really trust any of them that much, because I don’t know them! I’m sure they’re fine—they have degrees and everything. But I just don’t know them that well since they keep switching.” On the other hand, other parents who knew their child’s doctors longer generally trusted them. For example, one father noted that his two daughters saw the same pediatrician that he did when he was young: “I’ve known him [the pediatrician] my whole life, so of course I believe him.”

Given the frequency with which focus group participants linked their trust in their children’s doctors with the length of time they had known those doctors, a question asking about this duration was written and included in the initial questionnaire.

This question was administered in Rounds 1 through 4 to all respondents.

Findings

Respondents understood this question to be asking about how long they had known their child’s pediatrician. Their answers ranged from 4 months to 16 years. Two respondents answered “Don’t Know,” both indicating that their children did not have consistent doctors.

Q18: Do you have one or more persons you think of as your child's personal doctor or nurse?

1. Yes
2. No

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child’s access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child’s healthcare access and the parent’s interactions with healthcare providers. This question, specifically, was included as a way of capturing the parent’s experiences in relation to the previous question (Question 17) about how long they had known their child’s doctor. As noted in the Question Design and Background section for Question 17, some parents noted that they did not know their children’s doctors well (or for a long time),

because their child did not have a single healthcare provider. This question was taken from the National Survey of Children's Health (NSCH) questionnaire[11], and was intended to capture whether or not a parent had more than one "primary" provider, or someone (be it a doctor or nurse) that they believed was most responsible for providing healthcare to their child.

This question was only administered in Round 1.

Findings

Respondents interpreted this question in two ways, as shown below in Figure 5: by either thinking about whether or not they had more than one "primary" provider, or whether or not they had access to multiple providers:

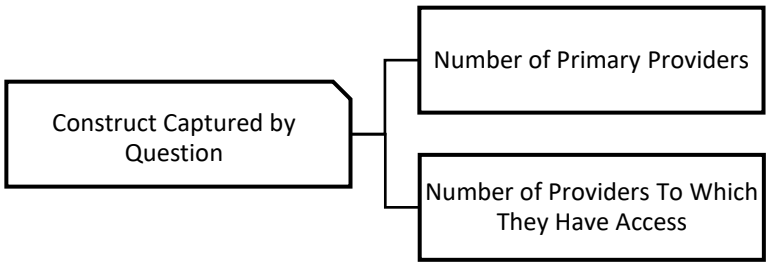


Figure 5: Patterns of Interpretation for Question 18

The distribution of these two interpretations was split relatively evenly across the respondents in Round 1, and both interpretations produced "Yes" and "No" responses. Respondents who used the first pattern focused on whether or not they considered more than one healthcare provider to be their child's primary source of care. When asked what she was thinking about when she answered the question, one respondent who said "Yes" explained, "If there's more than one doctor or nurse you think of as your child's doctor." She went on to note that she and her husband talk to the head nurse more than their child's actual pediatrician, so she counted both the nurse and the doctor. Another respondent answered "No" and said that while they go to a practice with a number of pediatricians, they typically see only one of them and consider her to be their child's primary care provider.

[11] http://childhealthdata.org/docs/default-source/nsch-docs/2016-nsch-guide-to-topics-and-questions_05-15-17.pdf, Question D1

However, other respondents took a broader view of the question and considered whether or not they had access to multiple doctors or nurses, not just whether or not they typically used the services of multiple providers. For instance, one respondent who answered "Yes" took the opposite approach of the previously quoted respondent above, and explained that she was thinking about the fact that her son went to a pediatric practice with multiple doctors. Upon follow-up, she revealed that he typically only saw one of these pediatricians.

Q19: During the past 12 months, are you satisfied with the amount of time that your child's doctors and other health care providers spend with [him/her]?

1. Yes
2. No

Question Design and Background

During the focus groups, respondents were asked to individually list both their most trusted and distrusted sources of information about childhood vaccines. When these data were analyzed across all of the focus group participants, doctors and other healthcare providers appeared to be highly salient (using Smith's S, a metric that combines both aggregate frequency and rank across all the lists, see Smith 1993) as both a trusted and distrusted source. During the focus group discussions, this discrepancy was explored and participants noted that while they may trust their individual doctors (especially if they had interacted with them for a long time, see Question 17 above), they largely believe that doctors (and the whole healthcare complex) are more interested in profit than care. They discussed this doubt in terms of whether or not their children's doctors had "their best interest at heart" when interacting with their patients. One of the qualitative metrics they noted that indicated this quality was the amount of time the doctor spent with their children—if it was an "in-and-out" scenario, where the interaction felt rushed, the parents were more likely to believe that the doctors did not have their child's best interests at heart.

Given this, Question 19 was included in the initial question in an attempt to capture whether or not respondents were satisfied with the amount of attention their child's doctor gave them. This

question was adapted from similar questions on the National Immunization Survey- Child (commonly referred to as the NIS-K)[12] and the NSCH[13].

This question was administered to all respondents in the first four rounds of cognitive testing.

Findings

Respondents considered one or more of three concepts surrounding their satisfaction with the "amount of time" their child's healthcare provider typically spent with them: how available the doctors made themselves, how "rushed" or not their appointments felt, and the quality of their interaction with the doctor.

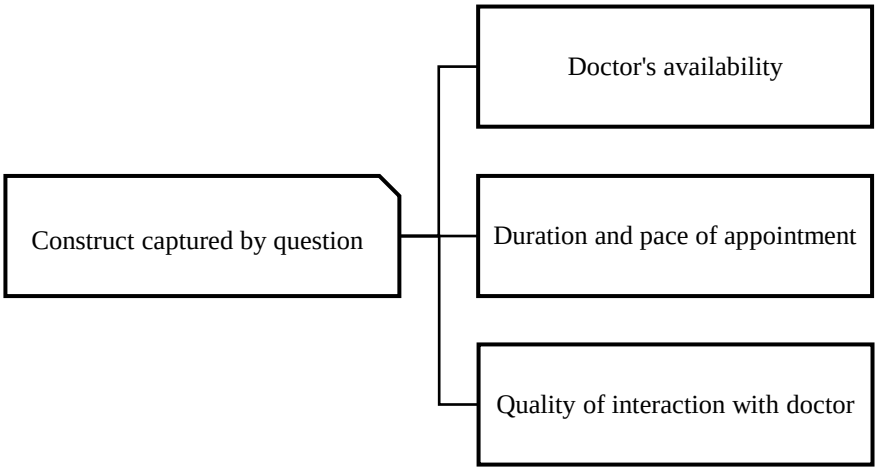


Figure 6. Patterns of Interpretation for Question 19

Respondents who understood the question in terms of their child's doctor's availability considered how easy it was to schedule an appointment or how easy it was to get in touch with the doctor in case of an emergency or late at night. For instance, one respondent who answered "Yes" explained what she was thinking by saying, "the doctor is always available to answer questions by email." However, another respondent answered "No," explaining that: "My child's doctor cut down on [appointment times] to just Tuesday and Thursday," so now she has to either fit her schedule around these limited openings or use an unfamiliar doctor at the practice.

[12] Question A27
[13] Question D4a

Other respondents focused their response on the amount of time they actually got to interact with the doctor during the appointments. For instance, a number of parents who answered "Yes" indicated that they did not "feel rushed" during the appointments, and that they feel like the doctor takes the time to answer all their questions. On the other hand, some respondents who answered "No" explained that they did "feel rushed" and were not given all the time with the doctor that they wanted. For example, one respondent explained his "No" answer by saying that "We used to have more time to discuss [his child's health with his doctor], but now the practice sticks with a strict 15 minutes per visit schedule" and that he was not at all happy with this change.

Finally, a few respondents appeared to base their answer not directly on either their doctor's availability or the duration of the visits, but rather on the quality of their interactions. For example, one respondent said that she was thinking about the fact that "they [the doctor's office] make sure we have no questions by the time we leave" and that she never feels like she does not have an opportunity to ask questions. Similarly, another respondent explained his "Yes" answer by noting that the doctor was very "collaborative" and he never felt as though the doctor "shut me down" or ignored his questions.

Q20: During the past 12 months, are you satisfied with how carefully your child's doctors and other health care providers listen to you?

1. **Yes**
2. **No**

Question Design and Background

Similar to the previous question (Question 19), the decision to include Question 20 in the initial questionnaire stemmed from the focus group discussions, where participants noted that they tended to trust doctors more if they believed that they had their children's "best interests at heart." Whether or not a doctor listened to the parents' concerns, and appeared to take them to heart, was an indicator to the parents that the doctor did indeed care more about providing high-quality care than simply getting money.

This question is adapted from a similar question (that asks about frequency instead of satisfaction) on the NSCH[14]. This question was only administered in Round 1.

Findings

This question was not probed systematically, and no findings are available.

Q21: When your child is seen by doctors and other health care providers, are you satisfied with the level of sensitivity they showed to your family's values and customs?

1. Yes
2. No

Question Design and Background

Similar to the previous two questions, Question 21 was included to capture the respondents' underlying comfort and satisfaction with their child's doctor. As mentioned above, the focus groups indicated that parents who were more satisfied with their child's pediatricians and other healthcare providers were more likely to trust them when it came to making vaccination decisions.

This question is adapted from a similar question (that asks about frequency instead of satisfaction) on the NSCH[15]. This question was administered to all respondents in Rounds 1 through 4.

Findings

While all but 1 of the 39 respondents who received this question in the first four rounds of testing answered "Yes," there was less unanimity in the interpretation of the question. While some respondents interpreted this as intended—thinking about whether or not the child's doctor or doctors took the family's values and customs into account when providing care—others interpreted the question to be asking about respect more generally:

[14] Question D4b
[15] Question D4c

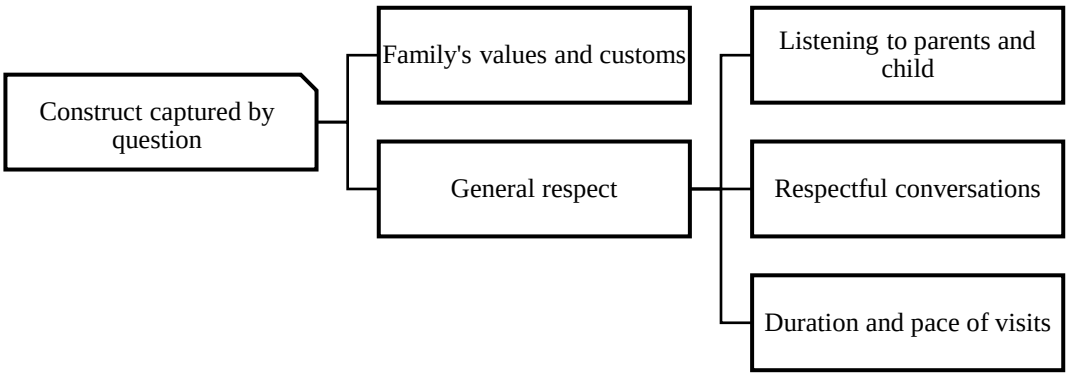


Figure 7. Patterns of Interpretation for Question 21

Respondents thinking about whether or not their children's doctors took their values and customs into account all considered whether and how the doctor melded his or her medical ideas with the family's culture. This ranged from religious customs to hesitancy about vaccines in particular or Western Medicine more generally. For example, one respondent who answered "Yes" explained her answer upon probing by saying that her daughter's pediatrician shared her "less medicine is better perspective" and agreed to limit drugs to when they were absolutely necessary.

Most respondents, however, did not focus on how the doctor dealt with their individual family's customs and values, but instead understood the question as asking more generally about whether or not they felt respected by the pediatrician. Respondents conceptualized this respect in a few ways. First, some considered whether the doctors listened to them and their child. For example, one who answered "No" explained "Some do, some don't. It depends—some are great, they listen to the kid and take their time. Others don't really listen to the kid." Others thought about whether the doctors answered all of their (and their children's) questions and had real conversations with them. One respondent who answered "Yes" for instance said she was considering, "Does the doctor treat my questions with respect?" She said that he does, and seems to take the time to explain things to her and does not dismiss her concerns. Finally, a few other respondents linked respect to the amount of time the doctor typically spends with them and their child—in essence, answering a question similar to Question 19 above.

Q22: During the past 12 months, are you satisfied with the amount of information given from your child's doctors and other health care providers about your child's care?

1. **Yes**
2. **No**

Question Design and Background

Similar to the previous questions, Question 22 was included in the initial questionnaire in an attempt to capture parents' satisfaction with their children's doctors. A recurring theme during the focus groups was that many parents did not feel like they had enough information about vaccines overall to be completely confident in their vaccination decisions. This question was specifically included to determine if the parents felt like their doctors gave them enough information to make sound medical decisions for their children.

No similar question was included on any of the source questionnaires, and this question was designed *de novo* for this project. This question was administered to all respondents in Round 1 only.

Findings

All respondents in Round 1 who received this question answered "Yes." This question was not systematically probed, and no findings are available.

Q23: During the past 12 months, did you feel like a partner in your child's care by your child's doctors or other health care providers?

1. **Yes**
2. **No**

Question Design and Background

This question, like the previous ones, attempts to capture whether or not the respondents were satisfied with their experiences with their child's doctors. This question was adapted from a similar question on the NSCH[16].

[16] Question D4e

Question 23 was administered to all respondents in Round 1, but was not on the Round 2 through 5 questionnaires.

Findings

All the respondents who received this question understood it to be asking whether or not their child's doctor included them in the child's medical decision-making process.

Q24: During the past 12 months, are you satisfied with the quality of medical care provided to your child by your child's health care providers?

1. **Yes**
2. **No**

Question Design and Background

This question, like the previous ones, attempts to capture whether or not the respondents were satisfied with their experiences with their child's doctors. This question was written *de novo* following the focus groups.

Question 24 was administered to all respondents in Round 1.

Findings

All the respondents who received this question understood it to be asking whether or not they were satisfied with the level of medical care they received from their child's doctor.

Q25: During the past 12 months, are you satisfied with the range of options your child's doctors or other health care providers considered for your child's health care or treatment?

1. **Yes**
2. **No**

Question Design and Background

This question, like the previous ones, attempts to capture whether or not the respondents were satisfied with their experiences with their child's doctors. This question was written *de novo* following the focus groups.

Question 25 was administered to respondents in Round 1 only.

Findings

Respondents all understood this question to be asking about whether or not the doctor considered reasonable options for their child's care. All but one respondent answered this question "Yes," while one respondent answered "don't know," explaining that his child had never been sick or injured, so he did not believe the question applied to his experience.

Q26: During the past 12 months, did your child's doctors or other health care providers make it easy for you to raise concerns, ask questions, or disagree with recommendations for your child's health care?

1. Yes
2. No

Question Design and Background

As noted above, one of the themes that emerged from the focus groups was that respondents who trusted their doctors were less likely to describe feelings of vaccine hesitance. One slightly counterintuitive aspect of this trust was the ability to disagree with the doctor—focus group participants explained that if they felt comfortable enough to disagree or bring up tough questions with their child's doctor, it was an indication that the doctor would treat them with respect, which in turn engendered feelings of trust.

This question was taken from the PACV question set[17], and a similar question is used on the Longitudinal Mother's Survey[18]. Question 26 was administered to all respondents in Rounds 1 through 4.

Findings

This question proved to be complex, with respondents understanding it using three separate patterns of interpretation. The root of this complexity is the fact that some respondents

[17] Question 17
[18] Baby Information Seeking and Sharing Section

understood Question 26 to be a double-barreled question, asking about both their ease of asking and their ease of disagreeing with their child's doctor, while other respondents only considered a single of these "barrels" and thought about either their ease of asking or ease of disagreeing with the doctor. These three patterns of interpretation are illustrated in the schema below:

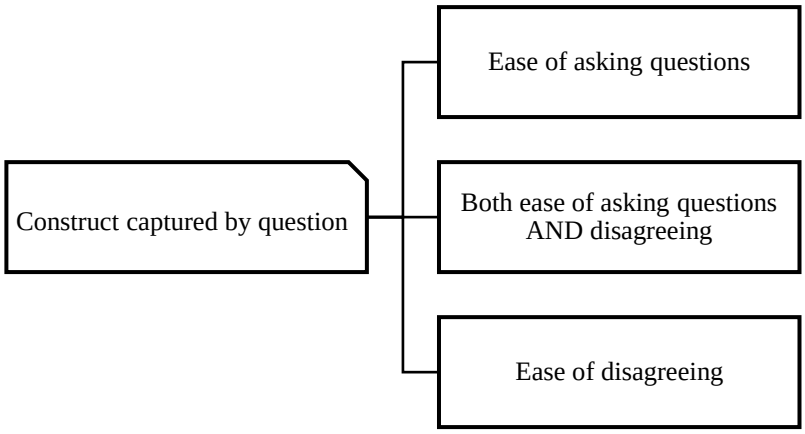


Figure 8. Patterns of Interpretation for Question 26

It is important to note that none of the respondents in the cognitive test interpreted this as a triple-barreled question: Even though the question text references three actions—the ability to "raise concerns," "ask questions," and "disagree"—respondents focused their responses on the latter two only, and appeared to lump "raising concerns" in with "asking questions."

Some respondents interpreted this question as a double-barreled question, and considered whether or not they believed that their child's doctor made it easy to both ask questions and disagree with them. For instance, when asked to explain why she answered "No" to this question, one respondent said, "I can ask questions, but not all of them [the providers, including nurses and pediatricians] like it very much when I disagree with them. They have to do what I say, but they don't like it, you can tell." So, while this respondent did believe that she could easily ask questions of her child's healthcare provider, because she also did not feel comfortable disagreeing with them, she decided that she could not answer "Yes."

Respondents who were thinking only about the ease of asking their child's medical professionals questions focused on whether or not they did (or would) feel comfortable asking their doctor for more information, or whether or not their child's doctor provided an environment conducive to

asking questions. For example, one respondent who answered "Yes" explained her answer by saying, "The doctor always makes sure I leave with no lingering questions." Another respondent, a first-time mother, who answered "Yes" explained that she felt comfortable going to the doctor with questions, even if she did not know if that was what she was supposed to do:

> A few months ago, [Child] had stuck a raisin up her nose, and I wasn't sure if I should call the doctor or not. But I did, and the doctor told me I made the right call—I felt validated. It's hard to make these decisions for your kid…whether or not to ask for care.

Similarly, other parents answered "No" because they did not believe that the doctor wanted them to ask questions or they just did not feel comfortable questioning a medical authority.

On the other hand, other respondents constrained their interpretation of the question to whether or not they believed they could easily disagree with their healthcare provider. For instance, one mother who answered "Yes" explained her response by saying:

> I do it [disagree] if I believe it. Others might find doctors intimidating, but I'll push back at them. But I can see if someone who doesn't have my personality, I can see them not being able to do it.

Likewise, another respondent who was thinking about whether he felt comfortable disagreeing with his son's doctor answered "No" and said, "He [the doctor] says what the treatment is, and he does not invite discussion…I've never disagreed with him, but I don't really feel like I can anyway."

Q27: During the past 12 months, did your child's doctors or other health care providers work with you to decide together which health care treatments choices would be best for your child?

1. **Yes**
2. **No**

Question Design and Background

Similar to the impetus for the previous question, Question 27 was included to capture whether or not respondents felt respected and if their child's doctors treated them like partners in their

child's care. This question was written *de novo* for the initial questionnaire, and was only administered in Round 1.

Findings

This question was not probed systematically, and no findings are available.

Q28: When you were selecting a doctor or health care provider for your child, was one of your considerations whether they would allow you to delay or refuse vaccines for your child?

1. Yes
2. No

Question Design and Background

Previous survey research, as well as the focus groups, indicated that parents who are vaccine hesitant are more likely than parents who are not to base the choice of their child's doctor or healthcare provider on whether or not that doctor will allow them to delay or refuse vaccination. For instance, during the focus groups, some parents noted that they explicitly searched for (or used their network to find) providers who were open to using alternative vaccination schedules, such as the Sears Schedule. Others simply included this fact as one of multiple characteristics upon which they based their decision. While most parents in the focus groups—even vaccine hesitant ones—explained that they based this decision on other factors (such as location, participation within an insurance plan, or cost), the ones who did indicate that the doctor's willingness to delay or skip vaccines appeared to be the most hesitant in the sample. As such, this construct was included in the initial questionnaire to serve as a proxy for strong vaccine hesitance.

This particular question is found on the 2016 National Poll of Parents questionnaire[19], and the construct is found on the Longitudinal Mother's Survey[20] questionnaire. This question was included on both the final 3- and 5-minute question sets, and was administered to all respondents in Rounds 1 through 5.

[19] Question KABS1
[20] Baby Information Seeking and Sharing Section

Findings

Respondents universally understood this question to be asking about whether or not they considered their child's doctor's stance towards delaying or refusing vaccines as part of their decision-making process when choosing the provider. However, there was variation in how the respondents actually based their responses. As illustrated in the schema below (which also shows which survey responses emerged from each pattern in the ovals on the right), respondents used three patterns of interpretation when deciding on what to base their response:

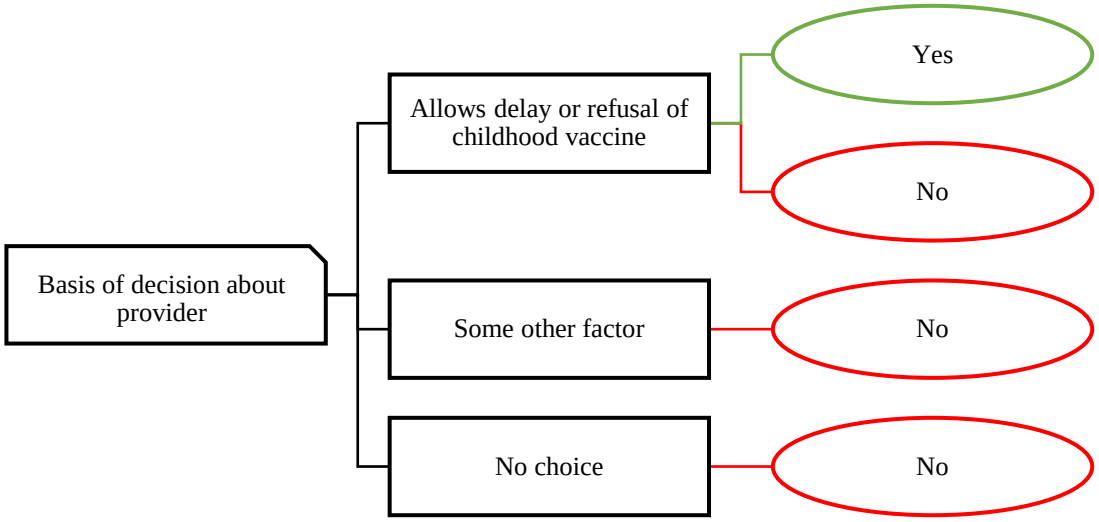


Figure 9. Patterns of Interpretation and Associated Survey Answers for Question 28

Directly considering whether or not their child's prospective medical provider allowed for vaccination delays or refusals lead to both "Yes" and "No" responses. Respondents who answered "Yes" were the people for whom this question was included—parents who had strong enough negative feelings about childhood vaccination that it affected their choice of doctor or healthcare provider. For instance, one mother who answered "Yes" noted that she was very wary of vaccinating her child because she had heard "a lot of horror stories" and was "concerned about all the reactions to vaccines" that her child might have. She said she was particularly worried about the standard schedule while she was searching for a pediatrician, saying that the standard schedule was "too much for a little tiny person with a little tiny body. You want to shoot my baby with what?? I'm sure it's fine for the majority of the population, but what if I'm the 1%?"

She went on, saying that she interviewed a few doctors in advance of choosing one so that she could discuss the option of not vaccinating her daughter. Respondents answering "No" who used this pattern of interpretation instead reported that they explicitly did not choose a doctor who would allow an alternative schedule, or that they explicitly wanted to follow the standard schedule. For example, when asked what she was thinking about when answering the question, one respondent who answered "No" said:

> If I went in and said I don't want to follow your vaccine schedule or CDC's vaccine schedule, and they were ok with that. That was not a consideration, because I want to follow that [the standard schedule]. I would be a little red flagged if they weren't as conservative [as in following the schedule conservatively]. I don't know that I would take my kids to a doctor who didn't follow the guidelines.

Most respondents who answered "No" reported that instead of basing their decision on whether a doctor would allow them to follow a delayed or abbreviated schedule, they primarily based their decision on other factors. These factors ranged from proximity to the parent's work or home, whether or not their insurance company worked with that particular provider, and whether or not the provider was recommended by family or friends. For example, one respondent who answered "No" in the fifth round explained why he answered that way by saying, "Our cousin uses it [the pediatric practice], and our friends use it. Also, one of their offices is super close to us, and they work out of the hospital that the kids were born at."

Finally, a couple of respondents explained that they did not technically make a choice about their provider, as their insurance company assigned their child's doctor. Both of the children had forms of managed care insurance (one was enrolled in CHIP/Medicaid, while the other was in an HMO). Both of these respondents answered the question "No," reasoning that the decision was not based on the doctors' stances on vaccination.

Q28a: When you were selecting a doctor or health care provider for your child, did you look for a provider who would follow the standard vaccination schedule?

1. Yes
2. No

Question Design and Background

Question 28a was designed to capture the opposite of Question 28—whether or not respondents picked their doctor based on the fact that he or she would administer childhood vaccines according to the standard CDC schedule. After three rounds of testing, it became clear that while Question 28 did a good job of capturing respondents who were strongly anti-vaccine (and thus added context to their response to the vaccine hesitancy scale question, see Question 35 below), it may be useful to attempt to capture the other side of that scale—that is respondents who were strongly pro-vaccine. This question was designed *de novo* with this construct in mind.

This question was included on both the final 3- and 5-minute question sets, and was administered to all respondents in Rounds 4 and 5.

Findings

This question was understood with a similar set of interpretations as Question 28, which it was designed to mirror. All respondents understood that this question was generally asking about whether or not they based their decision on their child's healthcare provider on whether or not they would administer vaccines according to a standard schedule. As noted above in the analysis of Question 5a, there was some variation around the term "Standard Schedule," all of which appear to be in-scope. In this case, respondents reported that they were considering things like the schedule approved by CDC, the American Academy of Pediatricians (referred to incorrectly in a few cases as the "American Pediatric Association"), the state government, or the local school district.

However, as before with Question 28, some variation emerged in how the respondents judged their answers to this question. This schema is illustrated below, with the survey responses that each pattern led to shown in the ovals on the right. As can be seen by comparing this schema to the one for Question 28 in Figure 9, the major difference in the interpretation of these two questions is that some respondents indicated that whether or not the doctor would administer the standard schedule was something they passively included in their decision. In other words, these parents considered whether the doctor's vaccination stance was a factor at all, even if it was not something that drove their search and decision.

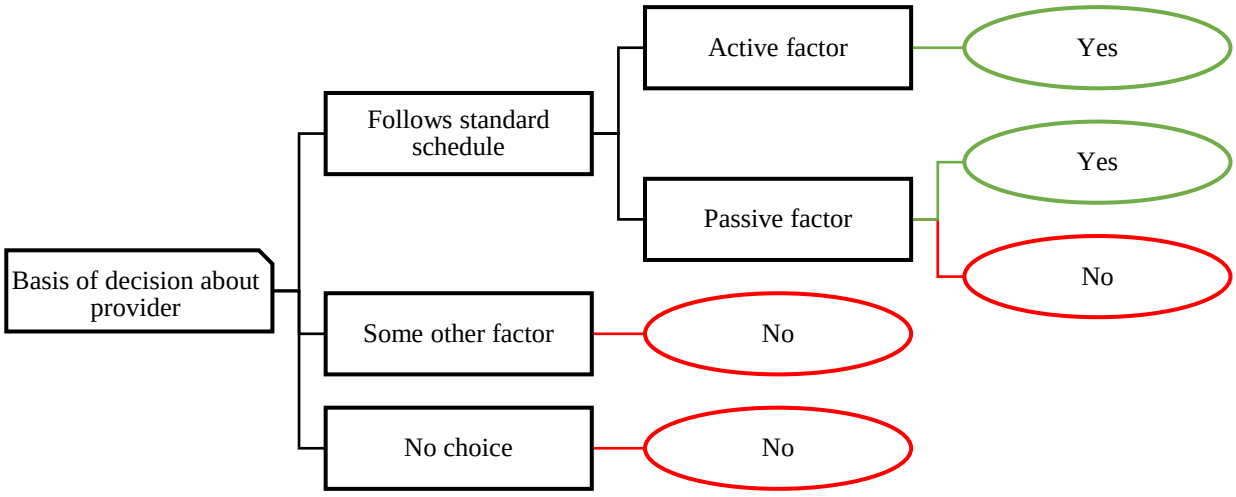


Figure 10. Patterns of Interpretation and Associated Survey Answers for Question 28a

For example, one respondent in the final round answered "Yes" and explained that if it turned out that doctors at the practice were "not fans of vaccination, we would have left!" However, upon further probing, when asked how she made the decision to pick this specific medical practice she indicated that its proximity to her house and work were actually the most important things she looked for. When asked about this discrepancy, she said that if the doctor did not follow the standard schedule that would have been a "red flag": "It was very important to me that they were vaccinating, but I guess it wasn't something I looked for…because we weren't trying to do anything abnormal."

However, other respondents who reported including the doctor's vaccination stance as a passive factor did not believe that just having this as an exclusionary factor counted for this question. For instance, one respondent answered "No" and explained that if a doctor did not insist on following the standard schedule it would be a reason to not choose that doctor: "They would not be doing the proper thing—they would not be doing their job." However, for this respondent, the fact that they had this exclusionary "floor" in their decision-making process was not enough for them to be able to answer that they did in fact "look for a provider who would follow the standard vaccination schedule."

Besides this added variation in whether or not respondents counted including this exclusionary factor when answering this question, the remainder of the patterns of interpretation seen in this

question are the same as those seen in the previous question about the opposite criteria. Respondents who actively searched for doctors who would only apply the standard schedule all answered the question "Yes." Likewise, respondents who did not consider the doctor's vaccination stance, but instead focused on factors such as location or availability all answered the question "No," as did respondents who indicated that they did not have a choice in who their pediatrician was because their insurance assigned them to a provider.

Q29: Do you believe that your child's doctors or other health care providers have [his/her] best interests at heart?

1. **Yes**
2. **No**

Question Design and Background

As explained in more detail in Appendix A, a component of the model used in the initial design of the questionnaire used in Round 1 was the child's access to healthcare. The questions in this section (Questions 7 through 29) were included in the initial questionnaire in an effort to get information about the child's healthcare access and the parent's interactions with healthcare providers.

This question was only administered in Round 1.

Findings

All 11 respondents who received this question in Round 1 answered "Yes" and appeared to be considering whether their child's healthcare provider put their child's interest ahead of their own. For instance, one respondent explained her "Yes" response by saying "he's [the doctor] not in it just for money, he's not interested in packing in the patients," suggesting that the provider could make more money if he gave less time to his patients. When asked to explain, another respondent simply said, "Of course." When pressed, this respondent explained that while it is true that doctors operate within a market system and must make money, their primary job is to care for children.

[Version 1 – Round 1]

Q30: Have you or your child personally ever tried any alternative medicine, like herbal remedies, acupuncture, chiropractic, energy or other therapies?

1. Yes
2. No

[Version 2 – Rounds 2 through 4]

Have you personally ever tried any alternative medicine, like herbal remedies, acupuncture, chiropractic, energy or other therapies?

1. Yes
2. No

Question Design and Background

A version of this question was included in a study on vaccine acceptance by the Pew Research Center on their 2016 American Trends Panel[21]. Subject matter experts at NCIRD suggested that the use of alternative medicines may function as a proxy marker of anti-Western Medicine and anti-corporate views and hypothesize that people who hold these views might have a larger-than-normal propensity to be vaccine hesitant. This question, and its follow-up Question 31, was included as an attempt to capture this population characteristic.

Two versions of this question were tested. Version 1, used only in Round 1, asked about "you or your child." Analysis of Round 1 data indicated that respondents understood this question to be double-barreled, and were correspondingly unsure whether to base their answer on their personal use of alternative medicines, or their child or children's use of alternative medicine. Version 2 of this question, used in Rounds 2 through 4, just asked about "you personally," thus eliminating the double-barreled character. The decision to focus the question on the respondent's use of alternative medicine (in opposition to the child's use) was made in consultation with NCIRD and based on the reasoning that the objective of this question was to obtain information about the parent's social attitudes in regards to Western medicine.

[21] See questions "BIO25" and "BIO26" on pages 91 and 92 of the report at http://assets.pewresearch.org/wp-content/uploads/sites/14/2017/02/01172718/PS_2017.02.02_Vaccines_FINAL.pdf

Findings

Overall Comprehension: Across both versions of this question, respondents considered a wide variety of treatments and supplements as "alternative medicine." This broad set of treatments includes:

- Herbal medicines and teas
- Chiropractic treatments
- Massages
- Acupuncture
- Natural food supplements
- Meditation
- Vitamins
- Exercise and yoga
- Marijuana

There is no "official" definition of alternative medicine, but on their face, none of these therapies or treatments appear to be out-of-scope. However, given the broad nature of this set of constructs, across the four rounds in which this question was administered, there was very little differentiation across the respondents' answers: 29 respondents answered "Yes," while only 10 answered "No." Furthermore, when compared with how respondents answered the vaccine hesitancy scale question (Question 35, see below), no clear trend between the use of alternative medicine and an individual's hesitancy towards childhood vaccines could be seen in the cognitive interviewing sample:

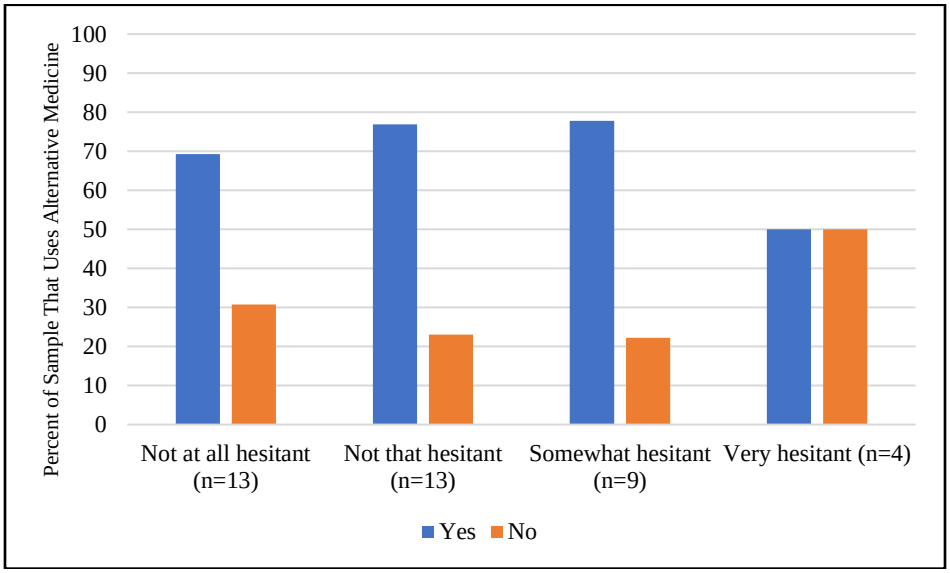


Figure 11. Chart showing the percentage of respondents who use alternative medicine, by childhood vaccine hesitancy scale point

Q31: The most recent time you used alternative medicine, did you use it instead of traditional medical treatments or in addition to traditional medical treatments?

1. **Instead of traditional medical treatments**
2. **In addition to traditional medical treatments**

Question Design and Background

Like Question 30 above, Question 31 is a slightly modified version of a question used on Pew's American Trends Panel in 2016[22]. As shown above, whether or not respondents use "alternative medicine" does not appear to differentiate between those who are hesitant towards childhood vaccines and those who are not. This question is designed to get at a deeper level of this use of alternative therapies and medicines, with the assumption that those respondents who indicate that they use alternative medicines instead of Western medicine are more likely to have anti-Western medicine attitudes that would affect their opinions towards childhood vaccines.

Question 31 was administered to the 29 respondents in Rounds 1 through 4 who answered "Yes" to Question 30.

Findings

All respondents who received this question understood it to be asking about the last time they used alternative medicine (or the last time they or their child used alternative medicine in Round 1).

Respondents who answered "In addition to traditional medical treatments" all explained that they had added some form of alternative medicine to some form of Western medicine. For instance, one respondent explained his "In addition…" response by saying, "I use homeopathic remedies for my colds and flu—but it's in conjunction with my doctor's advice."

Respondents who answered "Instead of traditional medical treatments" noted that they only used non-Western medicine the last time they used alternative medicine. However, most of these respondents explained that this choice was on a case-by-case basis. For example, one respondent

[22] See questions "BIO25" and "BIO26" on pages 91 and 92 of the report at http://assets.pewresearch.org/wp-content/uploads/sites/14/2017/02/01172718/PS_2017.02.02_Vaccines_FINAL.pdf

explained her "Instead of…" answer by saying "I used marijuana to help relieve the cough to get the mucous out of my chest. It's better than Mucinex!" However, this respondent went on to say that he typically used whatever medicine his doctor prescribed—it was just for this specific condition that he found non-traditional treatments to be more effective.

Q32: Do you trust the information you receive about shots?

1. **Yes**
2. **No**

Question Design and Background

Both the focus groups and previous research indicate that the more parents trust the information they get about vaccines from their doctors and other sources, the less hesitant they will be to fully vaccinate their children. However, there was no consistent source of information about vaccines that respondents either trusted or did not trust. An analysis of the freelist data provided by the focus group participants (see Appendix B) revealed, for instance, that both the doctors and the government were among the most- and least-trusted sources of information across the focus group sample. Question 32, therefore, was included in the initial questionnaire in an attempt to capture trust in information in a broad sense. This question was taken from the PACV question set (but with the answer categories modified into a Yes/No binary as opposed to a 4-point agreement scale)[23]. It is important to note that in the PACV, the intent of this question is to specifically capture parents' trust in the information about vaccines that they receive from their healthcare providers (Opel et al 2011: 421).

This question was administered to all respondents in Rounds 1 through 4.

Findings

Variation emerged in how respondents both comprehended and judged their answers to Question 32.

[23] Question 16

Comprehension: Two interpretations of this question emerged across the four round's worth of respondents who received Question 32. The first (and intended) interpretation was that the question was asking about whether or not the respondents trusted the information they received about their child's vaccines. However, other respondents understood the question to be asking more generally if they trusted childhood vaccines. This schema is illustrated below:

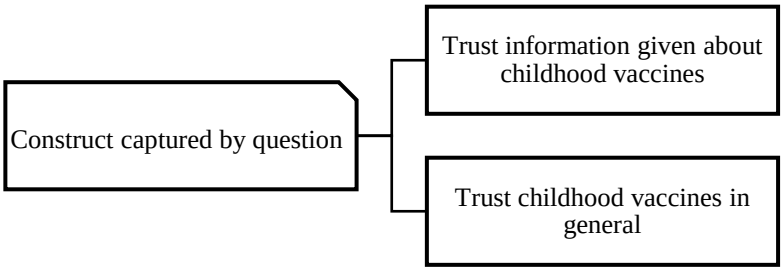


Figure 12. Patterns of Interpretation for Question 32

Most respondents used the intended interpretation. For instance, one respondent who answered "Yes" was asked to restate the question in her own words and said, "Do I believe them [thinking about the vaccines factsheets from the CDC that the pediatrician provides]? Do I think they're sound and based on evidence?" However, a smaller group of respondents interpreted this question in a much broader sense, and understood it to be asking about their trust in childhood vaccines in general. For example, one respondent who used this interpretation restated the question by saying, "Do I think the vaccines are really doing what they are supposed to do?" All of the respondents who used this out-of-scope interpretation answered "Yes" to Question 32.

Please note that the word "shot" was used in the question text, and was universally understood to be referring to all vaccines. Please refer to the Cross-questionnaire Findings section above, starting on Page 7, for a longer discussion of this terminology.

Judgment: Variation emerged in how the majority of the respondents who interpreted the question as asking specifically about trust in the information they received judged their responses. The schema showing the patterns of judgment is below, with the survey responses that each pattern produced shown in the colored ovals to the right:

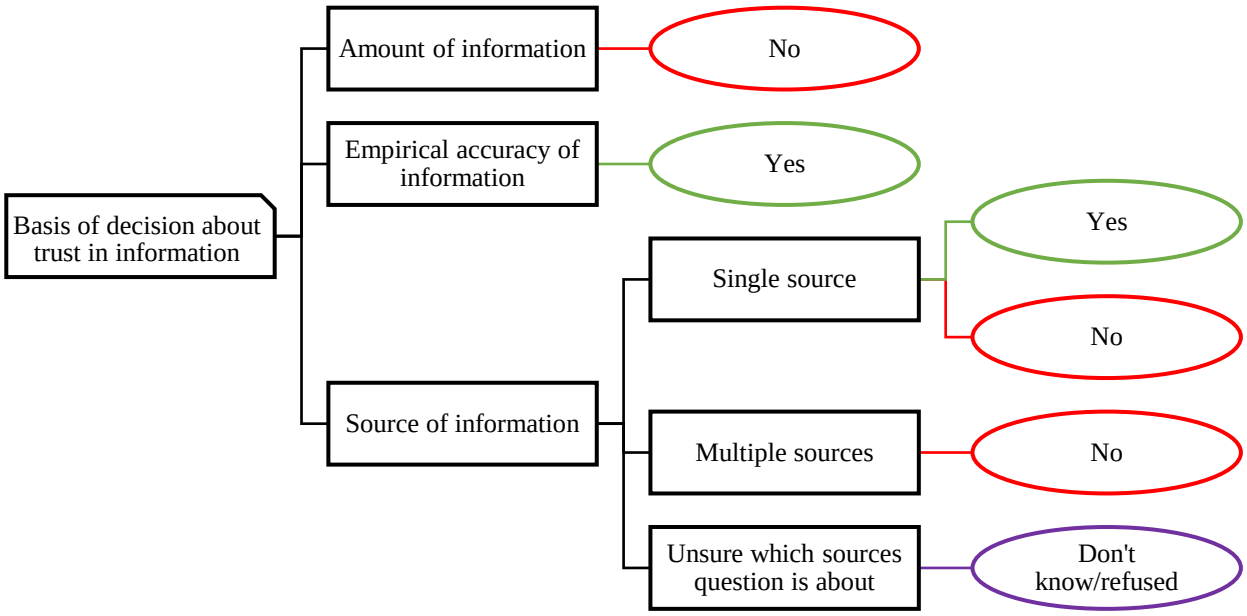


Figure 13. Patterns of Judgment and Associated Survey Answers for Question 32

A few respondents based their answers on how much information they believed they received. Both of these respondents answered "No," and indicated that they did not trust the information because they thought that they were not being shown all the information that is available. For instance, when asked to explain his answer, one respondent (who used the alternative Sears Schedule for his child) said, "I would say that I don't receive much information about shots. That's the main problem we have with the normal schedule, why are they all given together? I guess I would have to say no."

A couple of other respondents—all of whom answered "Yes"—based their decision on whether or not the felt like they had evidence that the information they received about childhood vaccines was accurate. For example, one respondent said that he thought the question was asking, "Do I know that they're [the vaccines] not going to have any side effects that I don't know about?" This father answered "Yes" because his child had never had any side effects that he was not told about by his doctor or other sources he and his wife consulted.

Most parents based their response on a judgment of the trustworthiness of a given source of information. Across the sample, parents thought about a wide variety of sources, including:

- Their pediatrician
- The CDC
- Other government agencies (such as the FDA)
- The vaccine "factsheet" they receive during doctor's appointments
- WebMD and other health-based websites
- Friends and family
- Facebook and other social media sites

While this is a broad set of sources of information, most of the variation in this pattern of judgment emerged not from how the respondents decided that something was or was not trustworthy or which source they were considering, but rather based on how many sources they believed the question to be asking about.

Most respondents conceptualized the question as asking about a single, specific source of information. They then judged their answers thinking only about this source. Many of these judgments were heuristic in nature—respondents immediately noted whether or not they believed the information coming from a specific source. For instance, one respondent who answered "Yes" simply noted that she was thinking of the information that she receives from her child's pediatrician, and that she trusts doctors. Respondents who used this pattern and answered "No" often admitted that they trusted other sources of information, just not the one they believed the question to be asking about. For instance, one respondent who answered "No" was thinking specifically about the information that she receives from her child's pediatrician. However, she went on to say that she does her own research on WebMD, and that she trusts what she finds there—so her "No" does not indicate that she does not trust *any* or *all* information about vaccines, just the information she receives from the particular source about which she believed the question was asking.

Other respondents did not limit their judgment to a single source of information, and instead believed that the question was asking about multiple sources (or all sources) of information on vaccines. These respondents answered "No," indicating that they could not say that all the sources they were thinking about were trustworthy. For instance, one respondent said that while he may trust what his son's doctor says, he does not believe he can trust pharmaceutical companies, so he felt like he had to answer "No." Likewise, another respondent explained her "No" response by saying, "It's important to consider the source: Is the information coming from

pharmaceutical companies? They're not trustworthy. Or is it coming from the government? They're trustworthy. I trust my doctor, too. But I don't trust everything."

Relatedly, a number of respondents answered either "don't know" or refused to answer because they were unsure either which sources they should be thinking about, or unsure how to express the fact that they trusted some sources but not others. For instance, one respondent who answered "don't know" explained, "I assume you're asking about my pediatrician. That's 'Yes.' But from what I see on the internet? 'No!' I'm not sure who you're asking about." Similarly, another respondent who refused to provide an answer explained her decision by saying, "From where? From my doctor? Yes. From information I receive from my stepmother's posts on Facebook? No…you have to specify the source of information. I trust doctors and I would trust the CDC, a legitimately grounded institution."

[Version 1 – Rounds 1 through 3]

Q33: Do you believe it is better for your child to develop immunity by getting sick than by getting a shot?

1. **Yes**
2. **No**

[Version 2 – Round 4]

Do you believe it is better for your child to develop immunity by getting sick or by getting a shot?

1. **Getting sick**
2. **Getting a shot**

Question Design and Background

Previous work exploring the reasons behind childhood vaccine hesitancy has indicated that a parent's belief in the power of "natural immunity" positively correlates with measures of hesitancy and negatively with vaccination outcomes (Prislin et al 1998; Salmon et al 2009). During the focus groups, a number of vaccine-hesitant participants noted that they preferred natural medicine over "chemicals." Many of these parents reasoned that since vaccines are typically just weakened viruses, a child getting sick with (and then beating) a virus is just as, if not more, effective than vaccines since their child would be relying on the strength of their bodies to gain the immunity. Given this concordance between the literature on vaccine hesitancy and the focus group findings, Question 33 was included in the initial questionnaire in an attempt

to capture this specific health belief. This question was taken directly from the PACV (though the answer categories were modified away from the PACV's 4-point agreement scale)[24]; it is also found on the National Poll of Parents[25].

Two versions of the question were administered and tested. The first version, used in Rounds 1, 2, and 3, used a binary Yes/No set of answer categories. These response options confused a number of respondents, who had difficulty understanding whether "Yes" indicated they agreed with their child "getting sick" or "getting a shot." In Round 4, the Yes/No binary was replaced with these two phrases, and the question text was modified slightly to clarify that the respondents should answer either "Getting sick" or "Getting a shot."

Findings

Across both versions, respondents largely understood this question to be asking about their preference in regards to how their children obtained immunity from diseases. Variation did emerge in both the judgment and response stages.

Judgment:

A small amount of variation in what the respondents based their answers on was present across both versions of Question 33. In short, there was disagreement over whether or not to base their answer on all childhood diseases or instead on a subset of childhood diseases:

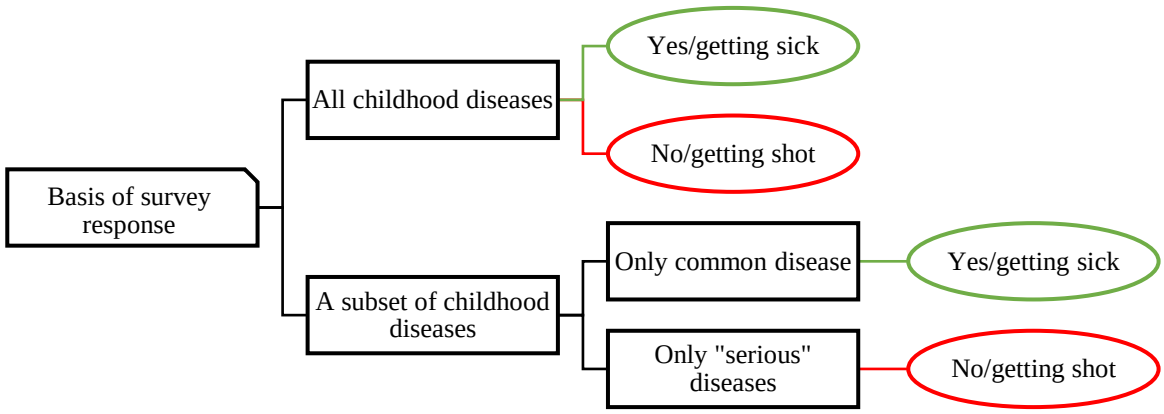


Figure 14. Patterns of Judgment and Associated Survey Answers for Question 33

[24] Question 9
[25] Question7_10

Some respondents based their answer on the entire universe of childhood diseases, with a "Yes" (in Version 1) or a "Getting Sick" (in Version 2) indicating that the parent would prefer that their child get their immunity "naturally" for all possible diseases; a "No" or "Getting a Shot" indicated that the parent would prefer that their child get immunity from a shot when that was possible. For example, one respondent who answered "Yes" was thinking about all diseases and expressed the opinion that natural immunity better prepared people than shots do:

> If you get sick, your body will know what it's like [to be sick with that particular disease], so it will know how to fight back. If she [his daughter] gets sick, she can prepare for what's to come; but if she gets a shot, she can't prepare.

Similarly, another respondent who answered "getting sick" to the second version of the question explained, "You don't know what's in the vaccine. Vaccines may cause problems later. This applies to all medicines and surgeries, too. Getting sick is more natural and better for the body." Other respondents who used this interpretation came to the opposite answer—for instance, one respondent who answered "getting a shot" to the second version of the question reasoned that while natural immunity may be great, in the end, she would prefer that her child did not have to suffer through being sick:

> The question sounds like it's saying, 'Would I rather take a preventative step like get my child vaccinated or introduce things into their body that they may not come into contact with?' Or just take a chance that if they do come into contact, their body's natural defenses will kick in and it won't be a problem for them in the future? I believe in the body's natural ability and potential to build up immunity against things. So, it would be great to say, 'Oh I would rather them build up immunity to things naturally.' But when it comes down to it, I don't want my children to be sick, so they get the shots.

Most respondents judged their answers not by considering all possible vaccine-preventable childhood diseases, but rather by limiting their consideration to a subset of these. Some respondents, all of whom answered "Yes" or "Getting Sick" (in Versions 1 and 2, respectively) only considered common diseases, such as the common cold, the flu, and chicken pox. For instance, one mother who answered "Getting Sick" to the second version of the question was thinking about the flu and colds and explained:

> Well, I think that getting sick is more natural. The body has a natural ability to heal itself. A cold can be cured by drinking tea. When she [her daughter] gets sick, her body will build immunity—the next time the illness occurs, her body will recognize the antibodies and will know what to do with them…For really rare

> or dangerous things, ok, shots might be better. But for the cold and flu and things like that, I would trust the body.

Another mother, who answered "Yes" to the first version of the question said:

> For example, it would be better to get the chicken pox than the vaccine. I thought about refusing the [varicella] vaccine, but it's hard to find anyone with the chicken pox, so I went ahead and got it for him [her son].

On the other hand, some respondents only considered serious (or less common) diseases—some of the most frequently mentioned were mumps, measles, and small pox. All of the respondents who used this pattern of judgment answered the question with either a "No" in the first version or "Getting a Shot" in the second version of Question 33. For example, one respondent's (who answered "No") immediate reaction upon hearing the question was to say, "I think it depends on what type of sickness we're talking about." After she picked "No" and upon further probing, she explained her choice, saying, "Do I want my child to get measles, mumps, or rubella? No! But I got the chicken pox, and I'm fine. So, it depends on the disease." Similarly, another respondent who answered "No" noted: "That's a hard one for me! If it's everyday stuff, then yes. If it's small pox, then no! But I don't think they're asking about the common cold here."

Response:

Respondents who were administered the first version of Question 33 (which featured a binary set of Yes/No answer categories) expressed confusion when attempting to map their response to one of the answer categories. Simply stated, they were unsure whether a "Yes" response indicated that they would prefer their child to get shots or obtain the immunity naturally. (The "correct" interpretation is the latter, with a "Yes" response indicating that the parent prefers natural immunity and a "No" answer indicating that the parent would prefer their child to get shots instead.) This led to a few cases in the first round that appeared to be response errors. For example, one respondent who answered "Yes" said that he thought it was better to develop immunity through shots because it avoids exposure to potentially deadly diseases. Even after re-reading the question multiple times, the respondent maintained his "Yes" response and explained, "Yes, it's better through shots." After the question was modified in Version 2, these response errors did not emerge.

Q33a: Do you believe this is true for all diseases for which vaccines are available, or just some diseases for which vaccines are available?

1. **All diseases**
2. **Some diseases**

Question Design and Background

As noted above, many of the respondents in Round 1 who answered "No" (in Version 1) or "Get a shot" in ("Version 2") of Question 33 indicated that they responded this way because they believed that sometimes it would be ok for their child to get immunity naturally instead of getting a shot, but that they did not want to indicate they did not believe in getting vaccines at all. After a number of parents who felt this way in Round 1 expressed this hesitation surrounding their answer to Question 33, a follow-up question was developed to see if the health belief they expressed in the previous question was universal across all diseases or not.

Question 33a was developed *de novo* for this purpose, and was asked of all respondents in Rounds 2 through 4.

Findings

Question 33a was designed as a formal embedded probe of Question 33; all respondents who received this question understood it to be asking about whether the answer they provided to the previous question was true for all vaccine-preventable diseases or just some of the vaccine-preventable diseases. Some respondents expressed confusion when answering this probe, reasoning that they did not know which diseases had available vaccines and which did not, so they had a hard time saying one way or another. For instance, one respondent who answered "Some disease" immediately noted upon hearing the question, "I don't know the full list of vaccines." She went on, explaining "Like, I guess I don't know about the chicken pox vaccines—I just found out it's a thing, and I haven't done the research yet."

Q34: Do you believe it is better for your child to get fewer shots at the same time?

1. **Yes**
2. **No**

Question Design and Background

According to both previous research and the focus groups led by NCHS, one of the most frequent concerns that parents have about childhood vaccines is that their child receives too many shots (or doses of vaccine) at once. In the focus groups, the reasons that emerged behind these concerns ranged from being worried that a small child could be "overwhelmed" by the number of separate vaccines or medicines at once, to the idea that vaccines that are administered together may interact in disadvantageous ways. Question 34 was taken direct from the PACV questionnaire (with a change in answer category from a scale to a binary Yes/No set of options)[26].

Question 34 was administered only to respondents in Round 1.

Findings

Nearly every respondent who was administered this question in Round 1 expressed some confusion over what they considered to be the vague wording of the question, specifically the phrase "fewer shots." Parents noted that the number of shots administered at once varied across doctors' appointments, and that they could not be sure what level they were being asked to compare against. For example, one respondent who answered "No" paused for a while after receiving the question and then said, "I think this gets at the 'At what age?' question. I don't think in general that getting multiple shots is bad or worse, I don't think it saves her from getting side effects—it just leads to fewer doctors' visits. But it depends on how many shots and how old she was." Similarly, another respondent (who answered "Don't know") was more explicit about her confusion. When asked what she thought the question was asking her, she said, "Does fewer shots mean fewer visits? Getting as many shots as possible at the same time? Less shots at the same time? I have no clue what it means."

[26] Question 10

Q34a: Do you believe that children get more shots than are good for them?

1. **Yes**
2. **No**

Question Design and Background

According to both previous research and the focus groups led by NCHS, one of the most frequent concerns that parents have about childhood vaccines is that their child receives too many shots (or doses of vaccine) at once (see Appendix B). In the focus groups, the reasons that emerged behind this concern ranged from being worried that a small child could be "overwhelmed" by the number of separate vaccines or medicines at once, to the idea that vaccines that are administered together may interact in disadvantageous ways. Question 34a was taken directly from the PACV questionnaire (with a change in answer category from a scale to a binary Yes/No set of options)[27].

Question 34a was administered only to respondents in Round 1.

Findings

Respondents universally understood this question to be asking about their attitudes about the total number of shots or vaccines that children receive. Importantly, they all comprehended the question to be asking about children in general, and not about the vaccines their child specifically had received. The two respondents who answered "Yes" noted that they believed their children were required to be administered more vaccines than were probably necessary. For example, one respondent who answered "Yes" explained his answer by thinking on a society-level scale: "Do I think we're overdoing it with shots? Yes…modern society has too many vaccines in general. Do we really need a vaccine for everything?" On the other hand, respondents who answered "No" focused on the fact that vaccines were really only developed when needed. One mother who answered "No" said that she trusts that all vaccines that are administered to children are "medically necessary."

[27] Question 8

[Version 1 – Round 1]

Q35: Overall, how hesitant about childhood shots would you consider yourself to be?

1. **Not at all hesitant**
2. **Not that hesitant**
3. **Unsure**
4. **Somewhat hesitant**
5. **Very hesitant**

[Version 2 – Rounds 2 and 3]

Overall, how hesitant about childhood shots would you consider yourself to be?

1. **Not at all hesitant**
2. **Not that hesitant**
3. **Somewhat hesitant**
4. **Very hesitant**
5. **Unsure**

[Version 3 – Rounds 4 and 5]

Overall, how hesitant about childhood shots would you consider yourself to be?

1. **Not at all hesitant**
2. **Not that hesitant**
3. **Somewhat hesitant**
4. **Very hesitant**

Question Design and Background

As the overall intent of this design and evaluation project, as well as the resulting 1-, 3-, and 5-minute question sets, is to explain parents' hesitancy and acceptance of childhood vaccines, Question 35 was included in the initial questionnaire to serve as the question sets' outcome measure. Simply stated, the questions for both the initial questionnaire and the three short sets were selected to explain respondents' answers to this question.

Three versions of this question were tested throughout this design and evaluation project. The first version, which was only used in Round 1, was pulled directly from the PACV questionnaire[28] (and is also found on the National Poll of Parents questionnaire[29]), and uses "Unsure" as the middle answer category. This specific answer category, and its placement, was problematic. Respondents were not clear whether "Unsure" meant that they did not have an attitude, or if it was designed to function as a "middle" point on a 5-point scale (akin to

[28] Question 7
[29] Question PACVHES

something like “Neither hesitant, nor confident”). Additionally, reading the term “unsure” was awkward in the middle of the other four points of the hesitancy scale during oral administration.

In an effort to alleviate these issues, Version 2 of this question moved the “Unsure” answer category to the fifth position following the 4-point hesitancy scale. This version was administered in both Rounds 2 and 3. While changing the position made the administration slightly less awkward than in the first version, respondents were still unclear what “Unsure” signified. When asked what they thought when they heard it, some respondents said, “no opinion” or “maybe it means you’re neutral?” However, others indicated they had no idea what it signified, and said “I don’t know what that is” and “It doesn’t make sense—how can you be unsure?” Across the first three rounds, only one respondent actually answered Question 35 using the “Unsure” answer category. When asked to explain, this respondent indicated that she was very hesitant about the flu shot, but not about other childhood shots. During probing, when pressed to make a choice on the 4-point hesitancy scale, she said that she would have picked the “Not that hesitant” choice if she had to.

Because of this confusion around the meaning of the term, the oddity of including a “Don’t know” type response on this question (and not to the other questions in the proposed question sets), and the desire to administer Question 35 as a forced-choice attitudinal question, Version 3 dropped the “Unsure” answer category entirely. This version was administered in Rounds 4 and 5, and is included on all three short sets of questions.

Findings

The interpretation of Question 35 was largely consistent across all three versions of the question. In addition to the issues surrounding the “Unsure” answer category noted above, only small amounts of variation emerged in the respondents’ comprehension of the question.

Comprehension:

All respondents understood Question 35 to be asking about their attitudes towards childhood vaccines. However, minor variation emerged in two areas: the number of children and the reference period the respondent considered. While most respondents appeared to limit their

consideration to just the child they had been answering the rest of the survey's questions about, a few parents answered about their opinions across all of their children. For instance, one respondent who answered "Not that hesitant" explained, "There are very few things [in life] that I'm 'not at all' hesitant about, especially having to do my children and their healthcare decisions."

The other minor point of variation occurred around the reference period the respondents considered. Most respondents understood the question as asking about their current level of vaccine hesitancy. For instance, while explaining his answer, one respondent who answered "Not that hesitant" said:

> It's a lot harder when they're a baby—I guess I'm more protective of a baby. When she [her daughter] got four shots at once, I freaked out! I was like, 'Holy Moly, that's a lot for a really little baby!' But I'm less freaked out now that she's older and bigger.

On the other hand, a few respondents did not limit their answers to just their current attitudes, but rather included their attitudes towards vaccines throughout their child's or children's life or lives. For example, one respondent who also answered "Not that hesitant" noted that she was very worried when her child received four shots at once, but that now she considers herself to be "pro-vax" and is not worried at all. Her "Not that hesitant" answer represented an "averaging" of her previous attitudes with her current attitude.

Judgment:

Respondents judged their answers to Question 35 by weighing the perceived benefits of childhood vaccines against the perceived risks. The respondents mapped their responses to one of the four answer categories as expected—with respondents who only considered the benefits answering "Not at all hesitant," while respondents who only thought about risks answering "Very hesitant."

For instance, one respondent who answered "Not at all hesitant" explained her answer by saying, "Vaccines are an important part of modern health when they are growing up, this makes them less vulnerable to getting major disease like measles, which is on the rise in certain countries."

Another mother explicitly considered a risk versus reward equation when explaining her "Not at all hesitant" answer:

> I guess I just believe that they are absolutely necessary. And I guess I understand why some people are hesitant if they believed that a shot impacted their child. But, I think that I …I have no question that vaccines are necessary…I guess it's because, even your tap water has stuff in it that you're not supposed to have all the time. And for the people who are hesitant about shots, it's usually because of what the shot contains. But in some way, shape, or form you're going to get what's in that shot anyway, so I just feel like dying from measles, mumps, or rubella is worse than what could happen.

Respondents who answered using the other three scale categories all equated some amount of risk with childhood vaccines. Respondents who answered "Not that hesitant" noted more benefits than risks, while respondents who answered "Somewhat hesitant" thought mostly about risks and only a few benefits. One father who answered "Not that hesitant" said that there are specific vaccines that he was concerned about, saying, "the HPV and the chicken pox vaccines are two that I'm just not that sure about—I think there's a lack of research." However, he went on to say that he and his wife were committed to vaccinating their daughter. A mother who also answered "Not that hesitant" also had an issue with the HPV shot and the flu vaccine, and furthermore reasoned that the "anti-vax" movement would not be able to propagate like it had if everything they said was absolutely not true. However, she also explicitly noted that the risk/reward calculation she considered lowered her overall hesitance:

> I can read where vaccines are safe and there's no links between vaccinations and certain conditions like autism. But then you see so much conflicting information out there and they may not be from credible sources but just the fact that it exists is enough to put a shred of doubt in my mind. I know that there's no certainties in terms of vaccination. You can tell me 100% beyond any shadow of a doubt that not one instance of any of the horror stories you hear about can be true. I think of vaccinating my children in terms of risks vs. benefits. Just things like common sense. Life expectancy post vaccination error and things like that. Obviously, it works. I would never want to see my child sick or die from something that could have been protected. So, the benefits far outweigh the risks. But I acknowledge that there is still some risk.

Respondents who answered "Somewhat hesitant" expressed even fewer benefits, and focused their explanations on their perceived risks of childhood vaccines. For example, one mother said that she answered "Somewhat hesitant" because she did not believe that vaccines were really that effective at preventing diseases and that she thought that a child benefits more from obtaining

immunity naturally than from getting it from a shot. However, she still wanted her child to get all her vaccines because "it's traditional to get them, and she'll need them for school anyway."

Quite a few respondents who answered "Somewhat hesitant" noted that while they may have issues with vaccines in general, it is easier to just get them rather than fighting against the institutions (like schools and daycares) that require them. While the benefits that respondents who answered "Not at all" and "Not that hesitant" reported were more related to the health of their children and to public health, the benefits that the "Somewhat hesitant" respondents thought about were more about giving their children access to institutions and social spaces.

Respondents who answered "Very hesitant" only considered perceived risks and the negative effects of getting vaccinated. While many of the respondents did note that their children were vaccinated, like the "Somewhat hesitant" respondents, they said they did so only because it was required and they would prefer it if they did not have to vaccinate them at all. For instance, one father who answered "Very hesitant" explained that he served in the army and was administered a lot of vaccines, none of which he felt like he needed. He reasoned that the vaccines his son was given are, likewise, unnecessary. Furthermore, his son has autism, and he blames the vaccines and the doctors who administered them, who are unable to explain why his son developed the condition. A mother who answered "Very hesitant" does not like the idea of injecting her son (or herself for that matter) with foreign substances:

> I'm into the holistic approach of things now, so that's why I said I'd be more hesitant thinking about vaccines for my son. I know with most vaccines, it's injecting the actual virus into you, and I don't like the thought of injecting a virus into our systems…it's slowly deteriorating the immune system...that's what I personally believe.

[Version 1 – Rounds 1 through 3]

Q36: Do you think that your child has received too many vaccines at one time?

1. **Yes**
2. **No**

[Version 2 – Rounds 4 through 5]

Did concerns about the number of vaccines your child gets at one time impact your decision to get your child vaccinated?

1. **Yes**

[Version 1 – Rounds 1 through 3]

2. No

Question Design and Background

One of the most frequently mentioned concerns that parents expressed about the childhood vaccination schedule during the focus groups was that their child or children receive too many vaccines (see Appendix B). This concern about the amount of vaccines actually covers two separate constructs: being worried about the amount of vaccines given per visit, and not being comfortable with the total number of vaccines on the childhood schedule. The former of these issues was more common, but was expressed in a few ways. Some parents believed that the actual volume of medicine put into their child was too great (especially for infants), while others worried about the interactions that different vaccines could have with one another if they were administered at the same time. Questions 36 through 39 were designed to explore the various aspects of this concern.

This question was revised between Rounds 3 and 4 to match the wording of the other "concerns" questions (Questions 38 through 47). The revised wording—using the phrasing "Did concerns about…impact your decision to get your child vaccinated?"—was used to frame the question as asking about concerns that directly impacted the respondents' decision-making processes (as opposed to something that they simply had theoretical concerns about). This change in wording appeared to work, and false positive responses in Rounds 2 through 5 were largely eliminated.

Question 36 was adapted from the HealthStyles[30] and National Poll of Parents[31] questionnaires. It was administered to all respondents in Rounds 1 through 5, and is included on all three of the final question sets.

Findings

Respondents largely believed that this question was asking whether or not their concerns about the number of vaccines their child was administered at once changed their vaccination behavior

[30] Question VCONC
[31] Questions 7_1 and 7_2

or beliefs. In general, respondents who answered the question "Yes" explained that the number of vaccines given at once was one of the reasons they were hesitant about vaccines, whereas respondents who answered "No" did not have this concern.

For example, one respondent who answered "Yes" explained her answer by saying, "I don't want her [daughter] to get stuck with five, six, seven, or even eight shots at one time!" She said that this was more of an issue when her daughter was small and the doctors tried to administer a lot of shots at once, but that she convinced the doctor to spread the shots out over three visits. Likewise, another respondent noted that he said "Yes" because one time he said that his daughter was supposed to be administered more than five shots at once, but that he delayed a number of the vaccines because he believed that a lot of vaccines at once "can overload a child and make them feel like crap." He went on to say that he did his best to limit the number of shots that she received at once to "three or four."

All of the respondents who answered this question "Yes" previously indicated in Question 35 that they were at least a little hesitant to childhood vaccines; no respondents who noted that they were "Not at all hesitant" answered this question "Yes."

Q37: Do you think that your child receives too many vaccines?

1. **Yes**
2. **No**

Question Design and Background

One of the most frequently mentioned concerns that parents expressed about the childhood vaccination schedule during the focus groups was that their child or children receive too many vaccines (see Appendix B). This concern over amount actually included two separate constructs: being worried about the amount of vaccines given per visit, and not being comfortable with the total number of vaccines on the childhood schedule. The former of these issues was more common, but was expressed in a few ways. Some parents believed that the actual volume of medicine put into their child was too great (especially for infants), while others worried about the

interactions that different vaccines could have with one another if they were administered at the same time. Questions 36 through 39 were designed to explore the various aspects of this concern.

Question 37 was adapted from a similar question on the PACV[32], HealthStyles[33], and National Immunization Survey (NIS) Teen and Child questionnaires[34]. This question was administered to all respondents in Rounds 1 through 4.

Findings

Respondents universally understood this question to be asking about the number (and not the volume) of vaccines that their children have ever received. For example, one respondent who answered "Yes," explained that he believes that his child has been administered more vaccines than necessary, but was not sure which ones specifically he would have preferred she not get: "My intuition tells me that she receives too many, but I can't tell you which ones."

There was some variation on what the respondents judged their answers—some respondents, like the one above, considered if all the vaccines their child received were necessary. Others thought about effectiveness, such as one respondent who also answered "Yes" and explained her answer by saying, "It's better to get sick than to get the vaccine." The judgment of respondents who answered "No" broke down along similar lines, with many parents indicating that they believed that all the vaccines were medically necessary (or at least that they trusted their doctor when she or he said that all the vaccines were necessary). Other parents considered whether they believed that their child received so many vaccines that they would not be effective—in other words, considering whether or not their child would be "overwhelmed" by vaccines. For instance, one father who answered "No" said that he understood the question to be asking, "Is my child overmedicated with vaccines? I don't think so, it seems like the right amount of vaccines."

[32] Question 5
[33] Question VCONC
[34] Questions A2 on both questionnaires

[Version 1 – Round 1]

Q38: Do you think that your child's immune system would be overwhelmed by getting vaccinated?

1. Yes
2. No

[Version 2 – Rounds 2 through 5]

Did concerns about whether your child's immune system would be overwhelmed impact your decision to get [him/her] vaccinated?

1. Yes
2. No

Question Design and Background

One of the specific concerns that emerged out of the focus groups and literature review was the idea that parents were worried that their children's systems would be overwhelmed by the amount of vaccines they received (see Appendix B). Throughout the discussions, it became clear that there was no single, quantifiable amount or number of vaccines that provoked this concern, but rather that it depended on the health and age of the child. So, for instance, one parent mentioned in the focus groups that the number of vaccines she was comfortable with her child receiving at once changed over time as her body (and therefore immune system) developed: "When [daughter] was a baby, I just didn't understand how she could have all those shots and nothing bad happen because of them. Now she's bigger, and I don't really think about it." Question 38 was designed to specifically capture parents' concerns about whether or not their child's immune system could handle all the vaccines the child received.

This question (as well as the other "concerns" questions—Questions 38 through 47) was revised between Rounds 1 and 2. The revised wording—using the phrasing "Did concerns about…impact your decision to get your child vaccinated?"—was used to frame the question as asking about concerns that directly impacted the respondents' decision-making processes (as opposed to something that they simply had theoretical concerns about). This change in wording appeared to be effective, and false positive responses in Rounds 2 through 5 were reduced.

This question was adapted from a similar item on the HealthStyles[35], NIS-K[36], and National Poll of Parents[37] questionnaires. Question 38 was administered to all respondents in Rounds 1 through 5. This question is included as part of the 5-minute short set.

Findings

Parents universally understood this question to be asking about whether or not they were worried that vaccines would overwhelm their child's immune defenses. After the change in wording occurred between Rounds 1 and 2, false positive responses observed in Round 1 were eliminated and respondents who answered "Yes" all considered whether or not this concern impacted their decision.

In Version 1, respondents focused solely on whether or not they were concerned about the child's immune system in relation to vaccines. For example, in Round 1, a father who was administered the original wording of the question answered "No" and said, "Huh, that depends. She's two-and-a-half years old now, so no. But if I was thinking about my newborn, the answer would be different." When asked to explain, this father noted that there was no reason to be worried about his older child, as she had grown large enough that he was not worried about the interactions between her immune system and vaccines, but that his newborn was still small enough that he did worry about this. When asked if that worry affected how he approached the vaccination schedule for his newborn, he said that it had no effect. Another respondent explained her "Yes" answer by saying "This is a persistent fear of mine! She's so tiny [referring to her infant daughter]." However, this mother also reported that her child was fully vaccinated and that she had never delayed a vaccine administration.

Parents who received Version 2 of the question considered not only whether or not they had a concern, but also whether that concern impacted their vaccination decisions. For instance, one respondent who answered "Yes" noted that, "This was our number one concern—we wanted to spread the vaccinations out so we didn't tax [her daughter's] immune system." Another

[35] Question VCONC
[36] Question A4
[37] Question KABS13_2u

respondent who answered "Yes" thinks that his son got sick from getting so many vaccines as a child, and is now "…against any future vaccines. I think it's better for the body to build its own immunity…not having to adjust to what's injected."

Respondents who answered "No" to Version 2 focused more on the first clause, and because they had no concerns, never considered whether or not their decisions were impacted. For example, when asked what she was thinking about when she answered "No," one respondent said, "Do I think her system will be overwhelmed by the number of shots? Would it be one too many—more than the body can handle? No." These respondents expressed no concern at all, and therefore never even considered whether or not that concern had an impact.

[Version 1 – Round 1]

Q39: Are you concerned with the volume of vaccines given to your child at one time?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 and 3]

Did concerns about the volume of vaccines given to your child at one time impact your decision to get [him/her] vaccinated?

1. **Yes**
2. **No**

[Version 3 – Rounds 4 and 5]

Did concerns about the amount of medicine in the shots impact your decision to get your child vaccinated?

1. **Yes**
2. **No**

Question Design and Background

As noted above, one of the concerns that was repeated throughout the focus groups was that children, especially small babies, are injected with too much volume of vaccine for their bodies to handle. Question 39 was included in the initial set in an effort to capture this construct.

Question 39 was revised twice throughout the process. The original question, adapted from the HealthStyles questionnaire[38], was only administered in Round 1. Like the other "concern" questions, it was revised between Rounds 1 and 2. The revised wording—using the phrasing "Did concerns about…impact your decision to get your child vaccinated?"—was used to frame the question as asking about concerns that directly impacted the respondents' decision-making processes (as opposed to something that they simply had theoretical concerns about). This revised version was used in Rounds 2 and 3, after which another change was made: rewording the question to ask about the "amount of medicine" instead of the "volume of vaccines." This change, administered in Rounds 4 and 5 (and then included on both the 3- and 5-minute question sets) was made to incorporate the vernacular that respondents actually used when discussing this question.

Findings

Respondents understood this question to be asking about either the volume or "amount" of the vaccines that their children were administered. While not all respondents appeared to consider the specific, scientific term "volume," most did understand the question to be asking in general about the amount of medicine or vaccine that was put into their child. For instance, one respondent who answered "No" indicated that he thought the question was:

> …asking about the amount that's given with that specific vaccine, and that can then go into how much [of the vaccine] can be given at one time. Do they have to give it periodically or how much can be given every six months? Can they give you a full 5 ml shot at one time?

Similarly, another respondent explained her "Yes" answer by saying that she was considering "the amount of serum that's in the shot. It's too much."

However, in the first three rounds of testing, which used Versions 1 and 2, some number of respondents interpreted the phrase "volume of vaccines given…one time" to be asking about the same thing as Question 36—that is the number of separate vaccines administered at a single visit with the child's healthcare provider. For example, one respondent who answered "Yes" to Version 2 of the question explained her answer by saying, "When saying volume, it's how many

[38] Question VCONC

shots they're going to give him. That's what volume means to me the loudest." Another respondent who was administered Version 2 made this point explicitly, "My concern was about the number of vaccines, not the number of needles or the amount of liquid in the shot, but the number they're giving him at once."

As the question was intended to capture parents' reactions to their concerns over the volume per shot, not the number of shots per visit, the question was reworded between Rounds 3 and 4. When probed about how they would describe the former concept, many parents in the first three rounds used the phrase "amount of medicine." To them, this differentiated between the number of vaccines and the content of the shots. This wording was incorporated into Version 3, which across testing in Rounds 4 and 5, appeared to largely limit the respondents' interpretations to the desired construct. For instance, one respondent who answered "Yes" explained that he was thinking about how the "amount of vaccine and other substances in the shot" concern him, and this led him to have detailed discussions about the necessity of the shots with his son's doctor. Another respondent who answered "Yes" reacted to this question saying, "It's concerning the amount of stuff that goes into her [daughter's] body. The vaccine and the other ingredients."

[Version 1 – Round 1]

Q40: When making decisions to get your child vaccinated, were you concerned about emotional discomfort your child might experience during vaccination?

1. Yes
2. No

[Version 2 – Rounds 2 through 4]

Did concerns about any emotional discomfort your child might experience during vaccination impact your decision to get [him/her] vaccinated?

1. Yes
2. No

Question Design and Background

The idea that parents did not like it when their child cried or seemed emotionally discomforted because of shots did emerge during the focus groups, but no participants indicated that this was a major factor in either their hesitancy or their vaccination decisions. Nonetheless, conversations with subject matter experts at NCIRD indicated that the fact that a child might be emotionally

scarred from the pain of shots is a potential reason for parents' vaccine hesitance. Question 40 was included in the initial questionnaire to capture this construct.

Question 40 was adapted from a similar question on the NIS-K[39], and was administered in Rounds 1 through 4.

As with the other "concern" questions, Question 40's wording was changed after Round 1 in an attempt to limit the number of false positive answers by focusing the question on the impact of a parent's concerns, and not just the presence or absence of that concern. As with this the other concern questions, this change in wording appeared to correctly limit parents' interpretations to the impact of their concerns about their child's emotional discomfort.

Findings

Across both versions of Question 40, parents universally understood the phrase "emotional discomfort your child might experience during vaccination" to mean their psychological discomfort due to the pain of getting a shot. For example, one parent who answered "No" to Version 2 of the question explained her answer by saying "I know that there's emotional distress—she cries. If it was just asking about whether she has emotional distress I would've said yes. But it didn't impact me." Another respondent who answered "Yes" to the first version of Question 40 explained his answer by saying, "[His son] cried, and that made me sad. A baby is worried and scared, and not able to comprehend what is happening. All he knows is that he's getting stuck with a needle and he doesn't know why."

[39] Question B8A

[Version 1 – Round 1]

Q41: When making decisions to get your child vaccinated, were you concerned about pain caused by the needle during the vaccine injection?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

Did concerns about pain caused by the needle during the vaccine injection impact your decision to get [him/her] vaccinated?

1. **Yes**
2. **No**

Question Design and Background

While Question 40 was designed to capture parent's concern over their child's emotional discomfort due to vaccination, Question 41 was included in the initial questionnaire to capture concern over physical pain due to shots.

This question was adapted from questions on HealthStyles[40] and the NIS-K[41]. It was administered in Rounds 1 through 4. Like the other "concern" questions, the question was reworded after Round 1 in an effort to limit the parent's judgment to whether or not their concerns impacted their vaccination decisions.

Findings

Parents universally understood this question to be asking about their concern over their child's physical pain due to the needles used during vaccination. Most parents described this in terms of their children crying after getting shots. For instance, one parent who answered "No" explained that she was thinking, "She cries, especially when the doctor uses a larger needle. I don't like it, but it doesn't matter—she's getting her shots."

[40] Question VCONC
[41] Question B8B

[Version 1 – Round 1]

Q42: When making decisions to get your child vaccinated, were you concerned about swelling at the injection site?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

Did concerns about swelling at the injection site impact your decision to get [him/her] vaccinated?

1. **Yes**
2. **No**

Question Design and Background

Subject matter experts at NCIRD suggested that previous research had indicated that the potential for swelling on their children's bodies is a concern for some parents that may lead to changes in vaccination behavior.

Question 42 was adapted from a similar question on the NIS-K[42]. Like the other questions in the "concerns" section, this question was reworded after Round 2 to focus the judgment of the respondent on whether or not their concerns impacted their vaccination decisions. This question was administered to all respondents in Rounds 1 through 4.

Findings

All respondents across the first four rounds understood this question to be asking about their concern about swelling at the point on their child's body where vaccines were injected. For example, one respondent who answered "Yes" to the second version of the question explained her answer by saying:

> Yes, I discussed it with my doctor. I was thinking about the swelling that's widely cited in the information, the sheets that they give out. He [her son] still got the shots, but I paid a lot of attention to his arms afterward to make sure there wasn't swelling or anything.

A few respondents who answered "Yes" to Version 2 of the question had similar interpretations—that because their concern about swelling and signs of an allergic reaction led

[42] Question B8C

them to pay more attention to the site of the injection, they should answer the question affirmatively, even though they did not alter their vaccination behavior.

[Version 1 – Round 1]

Q43: When making decisions to get your child vaccinated, were you concerned about your child getting a fever or other illness after being vaccinated?

1. Yes
2. No

[Version 2 – Rounds 2 through 4]

Did concerns about your child getting a fever or other illness after being vaccinated impact your decision to get [him/her] vaccinated?

1. Yes
2. No

Question Design and Background

Like Question 42, Question 43 was designed to capture whether the concerns parents had about a specific side effect of vaccinations led them to alter their decision-making process.

This question was adapted from a similar question found on the NIS-K[43], NIS-Teen[44], NIS-KAP[45], the National Poll of Parents[46], and HealthStyles[47]. Like the other "concerns" question, it was altered after the first round to focus parents' responses on whether or not their concerns led to changes in their vaccine decision-making process. It was administered to all respondents in Rounds 1 through 4.

Findings

In Version 1 of the question, while most respondents did indicate that they were concerned about fevers that followed vaccinations, they split on whether or not this concern led to a "Yes" response. For instance, one father answered "No" and explained that "…we were worried about possible side effects like fevers, because the doctor told us. So, we were expecting and on the lookout for them." However, upon follow-up, this respondent said that his son still received all his vaccinations so far, and that he would continue to do so. On the other hand, another parent

[43] Question B8D
[44] Question C3B
[45] Question 6F1
[46] Question 7_3
[47] Question VCONC

who answered "No" also noted that they were concerned and expected the fever, but that it would not affect her decisions.

A few other parents noted that they were not concerned at all. Some explained that this was because it is such an expected and common side effect. For example, one father who answered "No" explained his thinking by saying, "Concerned? No, I expected it. It's just a side effect." Others linked their lack of concern to their lack of knowledge and experience with their first child. For instance, another father who answered "No" said:

> I wasn't concerned until she got her one year shots, and then we went to Israel and she got really sick and projectile vomited for three days. And that sucked. And so now I'm probably concerned for my next child, but it's probably not going to stop me from getting his shots. If I knew that by, like, separating them he would get less vomity, then I'd do that.

Version 2 of Question 43 did not perform as well as the other modified "concern" questions, with all 13 of the respondents who answered "Yes" basing their answers not on whether or not their concerns led to a change in vaccination behavior, but rather that their concerns led them to a heightened sense of awareness. For example, when asked to explain her "Yes" response, one mother said, "Because if she [her daughter] gets a fever, I'll have to take her to the doctor and I'll miss work. And I need the money, because kids are expensive." Upon follow-up, this respondent said that she would absolutely still get her child vaccinated, it was just something she had to pay attention to and worry about.

[Version 1 – Round 1]

Q44: When making decisions to get your child vaccinated, were you concerned about the possibility of your child having a seizure?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

Did concerns about the possibility of your child having a seizure impact your decision to get [him/her] vaccinated?

1. **Yes**
2. **No**

Question Design and Background

Like the previous few questions, Question 44 was designed to capture whether the concerns parents had about a specific side effect of vaccinations led them to alter their decision-making process.

This question was adapted from a similar question found on the NIS-K[48] and the National Poll of Parents[49]. Like the other "concerns" question, it was altered after the first round in an attempt to focus parents' responses on whether or not their concerns led to changes in their vaccine decision-making process. It was administered to all respondents in Rounds 1 through 4.

Findings

Respondents interpreted this question (in both versions) in two ways. Many parents understood this question to be asking about one-off seizures that occur because of a reaction that their child's body could have to a vaccine. For example, one mother who answered "No" explained that she was thinking about "a seizure because of some ingredient in the vaccine" but answered "No" because "This might be a known side effect, but it's far too rare to rise to the level of concern." Along this line, most parents actually indicated that they had never even thought about seizures being a concern in relation to vaccinations. For instance, another mother who answered "No" said, "I don't think so, I've never even heard of anyone getting a seizure from a vaccine!"

While most respondents interpreted Question 44 in terms of one-off seizures related to a specific vaccine, a few others understood this question to be asking about concerns over a chronic seizure disorder. For example, one respondent who answered "Yes" explained that his daughter had epilepsy "so seizures are always on my mind." When asked how this impacted his vaccination decisions, he said that he probably did a lot more research, but that she still received all of her shots.

[48] Question B8E
[49] Question 7_3

[Version 1 – Round 1]

Q45: When making decisions to get your child vaccinated, were you concerned about long-term adverse side effects of the vaccine?

1. Yes
2. No

[Version 2 – Rounds 2 through 5]

Did concerns about long-term adverse side effects of the vaccine impact your decision to get [him/her] vaccinated?

1. Yes
2. No

Question Design and Background

During the focus groups, one of the biggest concerns parents expressed about vaccinations specifically (and childhood medicine more generally) was the risk of long-term side effects that would impact their children's futures. Long-term side effects, such as the potential for cognitive disorders and permanent injury emerged not only throughout the focus group discussions, but also as some of the most salient risks parents listed when asked to freelist the potential negatives of childhood vaccinations (see Appendix B). Parents largely appeared to understand that such long-term side effects are exceedingly rare; however, this did not appear to always alleviate the concern since parents weighed long-term, but rare side effects more heavily than more common, acute side effects. Take for example the following conversation from one of the focus groups held at NCHS:

Moderator: So, a lot of you wrote down side effects. What were you thinking about?

Participant 1: Like not just a headache or something. A fever. Something more severe—something that injures them.

Participant 2: You know, worrying about mental things. I know people say it's not true, I know you guys [CDC] say that, but I still worry. Things like autism, mental problems.

Moderator: So, you think things like autism are a risk?

Participant 2: A small risk, yeah. I mean, nobody knows, right? And it's such a big thing. My kids still get their shots, but you know…

Participant 3: It's in the back of your mind. Something you have to consider.

Participant 2: Probably not going to—definitely not going to change my mind [about getting children vaccinated]—but it's there. It's a risk.

From these focus group discussions, as well as from previous research and conversations with subject matter experts at NCIRD, it was clear that severe, long-term side effects—as rare as they may be epidemiologically—were a salient concern of parents that they brought to the table when making childhood vaccination decisions. Question 45 was included in the initial questionnaire to capture how this concern over long-term effects affected parents' vaccination decisions.

Question 45 was adapted from similar questions on the PACV[50] question set, and the NIS-K[51], NIS-Teen[52], NIS-KAP[53], and National Poll of Parents[54] questionnaires. As with the other "concern" questions, the question text was modified after Round 1 in an attempt to focus the interpretation on whether or not a parent's concern impacted their vaccination behavior. Question 45 was administered to all respondents in all five rounds of cognitive testing, and is included on the 1-, 3-, and 5-minute final short sets of questions.

Findings

Respondents across both versions of Question 45 interpreted the phrase "long-term adverse side effects" to mean serious reactions or issues caused by vaccines. The list of these issues includes:

- Autism
- Paralysis
- Serious allergic reactions
- Cognitive or mental developmental problems
- Death or life-threatening illnesses
- Illnesses or reactions requiring hospitalization

While respondents interpreted this construct as including a large number of specific issues, these can all clearly be understood as long-term and adverse issues, and thus appear to be in scope. Interestingly, a few respondents (all of whom answered "No") indicated that the long-term adverse side effects that they were thinking about were the risks associated with them *not* getting their child vaccinated. For example, when asked to explain her "No" response, one mother said,

[50] Question 11
[51] Question B8F
[52] Question C3C
[53] Question 6F1
[54] Question 7_3

"I've never seen a long-term risk to getting them [vaccines]; I've seen a long-term risk to not getting them."

Besides their interpretation of the question's construct, respondents used three major patterns of judgment when determining their answer. These patterns, and the survey responses they elicited, are shown below in Figure 15.

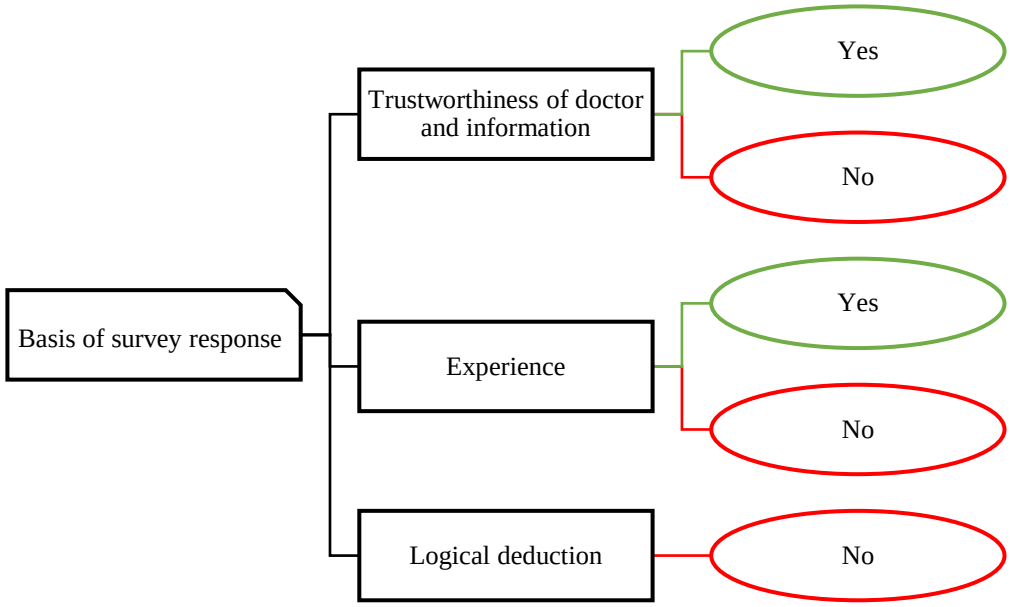


Figure 15. Patterns of Judgment and Associated Survey Answers for Question 45

The most common pattern of judgment across the cognitive sample was when respondents considered the information they had about childhood vaccines and made a judgment based on whether or not they trusted it. For many respondents who answered "No," this came down to simply trusting their pediatrician and the information sheets about each vaccine they were given. For example, one mother explained what she was thinking about when she answered "No" by saying:

> Well, I'm thinking about anything that would impact their health in the future. Any sort of deficit or damage. And again, I trust that those who are providing and administering the shots have done the research…I have to trust that the side effects are so rare, so unlikely, that I'm confident that it's worth the risk.

This was a common theme across respondents who answered the question "No." It's not that they did not believe that long-term adverse risks were possible, but rather that they either trusted or understood that these risks were so rare that it did not affect their vaccination decisions.

On the other hand, a number of respondents indicated that they did not trust the information they were given, and therefore answered "Yes," indicating that the potential for long-term adverse side effects was something they considered when making their vaccination decisions. In most cases where the respondent answered "Yes," this pattern was expressed as not believing that enough information was available about the long-term impacts of the vaccine for them to be completely comfortable. For example, one respondent who answered "Yes" said that he was specifically thinking about the HPV vaccine and said, "I'm not concerned about the short-term or acute effects, but rather the longer ones…I don't think they know if the HPV [vaccine] has that risk yet since they're just starting the research."

Other respondents based their responses on personal experience—considering whether they themselves knew of anyone who had an adverse long-term side effect from a vaccine. For example, one respondent who answered "No," said "I got the vaccine and I'm healthy. All my other kids got vaccinated and they're all fine." On the other hand, another mother answered "Yes" and explained that her sister's son has autism. Her sister is convinced that it was due to her nephew getting vaccinated, so she is now concerned about getting her daughter vaccinated.

Finally, a few respondents—all of whom answered "No"—based their answers on logical deduction. This is similar to the way respondents used experience to arrive at a "No" answer, but instead of focusing on people they personally knew, these respondents more or less considered the population as a whole. For instance, one respondent explained his "No" response by saying, "There are plenty of children who get vaccines all the time, and they are fine. Clearly, adverse side effects are rare."

[Version 1 – Round 1]

Q46: When making decisions to get your child vaccinated, were you concerned about your child developing Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?

1. Yes
2. No

[Version 2 – Rounds 2 through 4]

Did concerns about your child developing Autism or an Autism Spectrum Disorder impact your decision to get [him/her] vaccinated?

1. Yes
2. No

Question Design and Background

Even though no evidence exists about a link between childhood vaccines and autism (see, for instance, Taylor, Swerdfeger, and Eslick 2014), previous research into childhood vaccine hesitance (Brown et al 2010) and the focus groups conducted by NCHS indicate that this continues to be a salient concern for some parents. Question 46 was included in the initial questionnaire to capture the specific concern about this link (as opposed to the more general construct intended by Question 45 above). As with the other "concern" questions, it was revised after the first round to clarify the intent of the question.

This question was based on similar questions included in the HealthStyles[55], NIS-K[56], and National Poll of Parents[57] questionnaires. It was administered to all respondents in Rounds 1 through 4.

Findings

Respondents interpreted this question as a more specific version of Question 45, understanding it to be asking specifically about autism. All respondents who answered this question "Yes" also answered Question 45 (about long-term adverse side effects in general) "Yes" and carried their pattern of response forward. Similarly, respondents who answered Question 45 "No" all answered this question "No" and used the same pattern of judgment to determine their response.

[55] Question VCONC
[56] Question A10
[57] Question 7_3

The three respondents who answered the more general Q45 "Yes," but this question "No" indicated that their concerns about long-term side effects were not specifically about autism.

[Version 1 – Round 1]

Q47: When making decisions to get your child vaccinated, were you concerned about the ingredients of the vaccine?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 5]

Did concerns about the ingredients in the vaccine impact your decision to get [him/her] vaccinated?

1. **Yes**
2. **No**

Question Design and Background

Throughout the focus groups, one of the major factors of parents' concerns that repeatedly emerged surrounded the ingredients in the vaccines and how they could potentially impact their children's health. This concern emerged in two basic forms: concerns about specific ingredients and concerns about not knowing what the vaccines contained other than the virus. For example, during one of the focus groups at NCHS, the following discussion occurred:

> Moderator: You said you were a little worried. About what?
>
> Participant 1: Well I don't know what's in the vaccines. Like are there things in there that are harmful to my daughter?
>
> Participant 2: Right, like they make vaccines with mercury.
>
> Participant 3: Well not anymore. They don't
>
> Participant 2: I read that it's still in some. And that can't be good. I mean, why did they ever put that in there? Vaccines are supposed to help you, and that's a poison.
>
> Participant 1: Mercury yeah. But also, the other things. It's not like that whole shot is just a liquid virus. What else is in there?

Beside mercury, other focus group participants mentioned specific ingredients such as saline and egg whites.

Question 47 was included in the initial questionnaire to capture whether or not these concerns about the ingredients in childhood vaccines impacted parents' decisions. Like the other "concern" questions, the question was revised after Round 1 to clarify the intent of the question. This question was based on similar questions in the HealthStyles[58], NIS-K[59], and National Poll of Parents[60] questionnaires. It was administered to all respondents in all five rounds, and is included on the final 5-minute question set.

Findings

Respondents universally understood this question to be asking about the contents of the vaccines their children were offered, though there was some variation in whether or not parents included the actual virus as an "ingredient." Some parents focused on just the contents of the vaccines, excluding the virus. For instance, one parent who answered "No" said that she was thinking about "Allergens. But my kid doesn't have allergies, so I'm not concerned." Most parents, on the other hand, included both the "active" and "inactive" ingredients—meaning the live or inactive virus and the non-virus components. For example, another respondent who answered "No" explained that he was considering, "The active thing—the vaccine—and the inactive thing—the solution. It can all be made in different ways…I'm not concerned about trace amounts of things, and am not looking up ingredients and stuff like that."

Just as in the focus groups, the respondents' concerns were based on either worries about specific ingredients or concerns about not knowing what the vaccine contained. For example, one respondent who answered "Yes" was thinking specifically how multiple viruses (given in one vaccine) interact with one another and might affect her child's health: "I'm worried about all those combination shots. When they're given together, what does that do?" In a similar vein, another parent noted that she delayed some vaccines since she was worried her son was being given too many viruses at once and it would "overwhelm" his immune system.

Other parents were concerned about the fact that they did not know what the vaccines actually contained. For example, one respondent who answered "Yes" explained her answer by saying

[58] Question VCONC
[59] Question B8G
[60] Question 13_2

she was thinking about, “The stuff in it. I don’t know what they’re putting in that stuff [the vaccine]. Because the pharmaceutical companies are all about the money.”

[Version 1 – Rounds 2 and 3]

Q48a: Has there ever been a time when you delayed or put off a vaccination for your child?

1. **Yes**
2. **No**

[Version 2 – Rounds 4 and 5]

Has there ever been a time when your concerns about childhood shots caused you to spread out or delay vaccinations for your child?

1. **Yes**
2. **No**

Question Design and Background

Following the analysis of the findings from Round 1, Question 48a was added to the questionnaire beginning in Round 2. In Round 1, a few respondents answered Question 48 (see below) with a “Yes” response and indicated that they had simply delayed a vaccine, but they were not sure whether or not to count that as “refused” or “decided not to get a vaccination” (Question 48’s question text). After discussing this with NCIRD colleagues between Rounds 1 and 2, the decision was made to include a question that explicitly asks about delaying vacations. Further, the team made the decision to insert this question directly before the refusal question to frame the latter question (i.e., by asking about delays first, respondents should only include true refusals in Question 48).

The initial design of Question 48a was adapted from similar questions on the PACV[61] and the National Poll of Parents[62] questionnaires. Following Round 3, the question was modified to clarify its intent: A preamble clause (“Has there ever been a time when your concerns about childhood shots…”) was added to focus respondents’ interpretations only on delays that occurred because of ideology, and not on things like missed appointments or doctors’ recommendations because a child was sick when an inoculation was scheduled.

[61] Question 1
[62] Questions 3

Question 48a was asked of all respondents in Rounds 2 through 5, and is included on the final 3- and 5-minute question sets.

Findings

The two versions of Question 48a were interpreted in slightly different ways. Version 1 (Figure 16), asked in Rounds 2 and 3, did not include any framing statement in regards to the delay, and instead simply asked whether or not a parent ever delayed or put off a vaccination for their child. On the other hand, Version 2 (Figure 17) was altered so that the question specifically asked about delays due to "concerns about childhood shots." Correspondingly, respondents who received Version 1 had a broader set of interpretations than those who received Version 2:

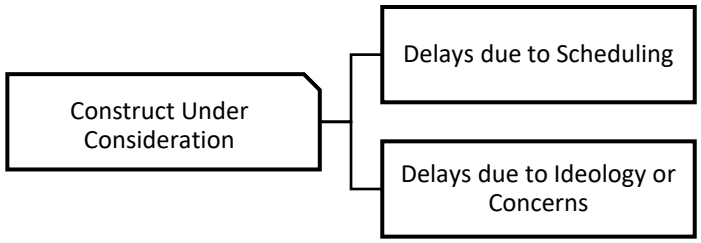


Figure 16: Patterns of Interpretation for Version 1 of Question 48a

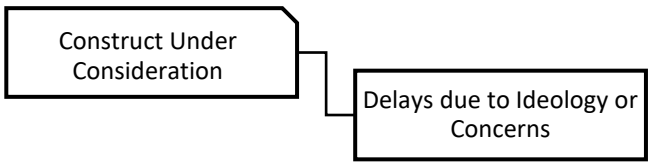


Figure 17: Patterns of Interpretation for Version 2 of Question 48a

While most respondents across both versions understood the question to be asking about delays due to concerns, because this was not explicitly stated in Version 1, a number of respondents who answered "Yes" indicated that they had relatively benign reasons for delaying their children's vaccinations. For instance, one mother who received Version 1 and answered "Yes"

explained that she had a home birth and was attended by a midwife instead of an OB/GYN or pediatrician, and that in her experience midwives do not administer the birth vaccines (i.e., the Hepatitis B shot given in the first day or so of life). She said that as soon as she took her son to his pediatrician for his two month check-up, he was administered the full slate of 2-month vaccines and was caught up on the Hepatitis B shot as well. Similarly, another mother who answered "Yes" noted that her daughter's doctor was supposed to give her a flu shot at an appointment the previous year, but because her daughter was sick the doctor told them to put it off until their next visit (which they did).

With the change in wording in Version 2, respondents limited their interpretation of the question to thinking only about delays due to their ideology or concerns they had about specific vaccines. For instance, one father explained his "Yes" answer by saying, "She [his daughter] is sometimes offered too many at once. So, I'll spread them out…two at a time is my limit. Any more than that and we'll come back for another appointment." Likewise, another mother noted that she had delayed the first measles shot because "I wanted to do more research." She answered "Yes" and went on to note that her daughter got the shot after she had delayed a few weeks until she was confident that it would not harm her.

[Version 1 – Rounds 1 through 3]

Q48: Has there ever been a time when you refused or decided not to get a vaccination for your child?

1. Yes
2. No

[Version 2 – Rounds 4 and 5]

Has there ever been a time when your concerns about childhood shots caused you to refuse or decide not to get a vaccination for your child?

1. Yes
2. No

Question Design and Background

Question 48 was included in the initial questionnaire to capture a direct outcome of parents' vaccine hesitance: refusal to get their child a scheduled vaccine. Just as with Question 48a above,

this question was adapted from a question on the PACV[63] and National Poll of Parents[64] questionnaires, and was altered after Round 3 to focus respondents' interpretations on refusals due to vaccine hesitancy. This question was administered to all respondents in Rounds 1 through 5, and is included on both the final 3- and 5-minute question sets.

Findings

As mentioned above in the analysis of Question 48a, in the first round there was no question on delaying vaccines, so a number of parents answered this question "Yes" and indicated that they were simply delaying a vaccine until they had more information. For instance, one father who answered "Yes" in the first round noted that he and his wife had decided to delay the Hepatitis B vaccine for their one-year-old and wait until "she needs it. It's not like she's having sex." Upon further probing, this father noted that they would eventually get their daughter the Hepatitis B vaccine at a later date (this family mistakenly believed that the Hepatitis virus was exclusively spread through sexual contact), and they were not refusing it *per se*.

After Question 48a was added the questionnaire in Round 2, respondents universally understood Question 48 to be asking about outright refusing to provide specific vaccines to their children. For example, one mother who answered "Yes" in the Round 3 noted that she had refused all vaccines for her three-year-old son so far, and that while his pediatrician was not in favor of this, he did not "force it on him" as long as her son comes in for well-child visits.

[63] Question 2
[64] Question 4

[Version 1 – Round 1]

Q49: Are you confident that all recommended childhood vaccines are safe for your child?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 5]

How confident are you that all recommended childhood vaccines are safe for your child?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

As noted above throughout the "concern" questions section, one of the major reasons that parents expressed childhood vaccine hesitance was that they were not confident that the vaccines (or their individual ingredients) were safe for their children. Question 49 was included in the initial questionnaire in an attempt to capture this confidence or lack of confidence, and was adapted from similar questions on the HealthStyles[65], PACV[66], Vaccine Confidence Scale[67], NIS-K and NIS-T[68], and NIS-KAP[69] questionnaires.

The initial version of the question, used only in Round 1, presented the respondents with a binary set of "Yes/No" answer categories. Analysis of the Round 1 data indicated that respondents found this binary set of options limiting. For instance, one respondent in the first round answered "No," but explained that "They're probably safe, but I'm not sure. Some kids do have serious reactions to vaccines." Upon further probing, this respondent indicated that he did not completely believe that vaccines were not safe for his child, but that he wanted a way to express his reservations. Due to this pattern of response, the decision was made by NCHS in consultation with colleagues at NCIRD to change the response categories for all the "confidence" questions from Yes/No to a three-point confidence scale ("Very confident," "Somewhat confident," and

[65] Question VCONFS
[66] Question 12
[67] Question 3
[68] Question A5
[69] Question4

"Not at all confident."). This revision limited the false negative answers (such as the one in the example above) by giving respondents a wider range of answer options.

This question was administered to all respondents in Rounds 1 through 5, and is included on the final 3- and 5-minute question sets.

Findings

While there was some variation in how respondents comprehended this question's construct and how they judged their answers, their interpretations are all in-scope and the question appears to accurately capture respondents' attitudes towards the safety of childhood vaccines.

Comprehension: Respondents interpreted the word "safe" either in terms of side effects or the efficacy of vaccines. Most respondents focused on whether or not recommended childhood vaccines had side effects. Respondents who answered the question "Not at all confident" were more likely to think about side effects in absolute terms—that is, they indicated that any side effects at all indicate that a vaccine is unsafe. For instance, when asked what she thought this question was asking, one mother who answered "Not at all confident" explained that she was thinking, "How long will the side effect last? Will it upset [her daughter]? Will they have a fever or soreness for days?" Similarly, another mother who answered "Not at all confident" focused specifically on the flu shot and said that it was not safe because it could lead to "…fever, chills, achy body and vomiting."

On the other hand, respondents who answered either "Somewhat confident" or "Very confident" explained that they were thinking about vaccine safety in terms of a lack of serious or severe side effects. For instance, one father who answered "Very confident" explained that he understood the question to be asking whether he believed that vaccines are "…unlikely to cause any serious, chronic health conditions or acute health problems. By serious, I mean something greater than swelling at the injection site or a low-grade fever."

In addition to conceptualizing safety as related to the presence or absence of side effects, a few respondents explained that they understood safety in terms of vaccine efficacy. For instance, one

respondent who answered “Not at all confident” explained her answer by saying, “They aren’t safe because they aren’t very effective at prevention.” She went on to say that natural forms of immunity—from getting the flu via the environment for instance—were safer and more effective.

Judgment: Respondents used a variety of strategies to judge their response to Question 49, including considering whether or not they trusted the process behind producing and approving vaccines, whether they have experienced or heard about safety issues, and whether or not they can be completely confident about the safety of all childhood vaccines. These patterns of judgment, as well as the survey responses that each pattern produced in the cognitive sample, are illustrated below in Figure 18:

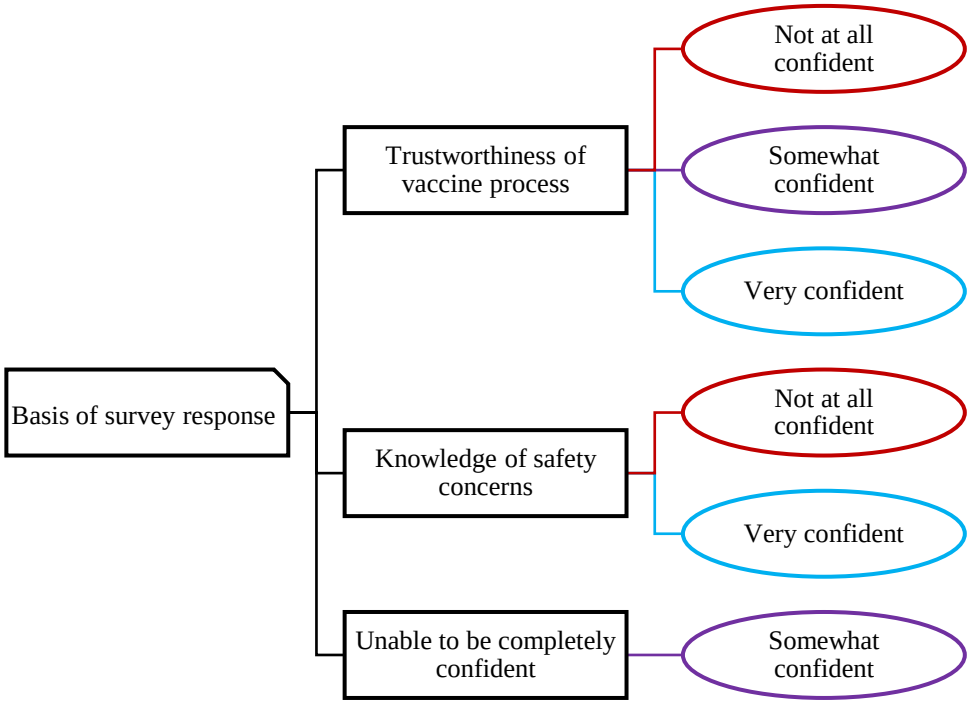


Figure 18. Patterns of Judgment and Associated Survey Responses for Question 49

Most respondents who answered “Not at all confident” and “Very confident,” as well as a couple of respondents who answered “Somewhat confident” based their answers on their trust in the vaccine production and approval process and on their trust in their doctors and their recommendations. Respondents who indicated that they did not trust this process answered “Not

at all confident." For instance, one father was asked to explain why he was not at all confident, and replied that he thought vaccines were being "rushed out" saying:

> These things are rushed out too fast. Instead of doing the proper testing, they're tested on the public. They [the pharmaceutical companies] are privatized, so they're trying to make money off it.

On the other hand, respondents who said they trusted the process (and their doctors) indicated that they were confident in the safety of vaccines. For example, one respondent who answered "Yes" (to Version 1 of the question) explained: "I believe in science. My confidence comes from my confidence in the scientific method, the integrity of scientists, research, and government agencies. I'm not concerned about conspiracy theories." Similarly, another respondent who answered "Very confident" noted that:

> Well, I have to believe that they'd [her doctors] lose their licenses if they're administering something that hasn't been tested. That's the best way to summarize this whole thing: I trust the system. There's a bunch of systems in place that control this whole thing and I trust them.

A few respondents, all of whom answered either "Not at all confident" or "Very confident" explained that they were basing their opinions of vaccine safety on information they had heard or on personal experience. For instance, one respondent who answered "Not at all confident" said that "I'm not at all confident that they're safe, I have no proof that they are safe. I've gotten the flu after getting the shot!" Another respondent considered the fact that they had not heard about any safety concerns, and because of that they felt "Very confident:" "If they weren't [safe], we'd hear about it more [in the media]."

Finally, a number of respondents who answered "Somewhat confident" explained their response by saying that while they generally believed that vaccines were safe, they could not be completely sure—and thus could not answer "Very confident." For instance, one father who answered "Somewhat confident" said, "I don't see how it can be 100% safe. You are trying to do in general what's best for the child and in general what's best for public health. But you can't be l00%."

[Version 1 – Round 1]

Q50: Are you confident that all recommended childhood vaccines protect your child from diseases?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that all recommended childhood vaccines protect your child from diseases?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

In addition to the belief in the safety of vaccines, the focus groups and previous research have suggested that belief in the efficacy of vaccines is an indicator of parents' overall confidence in childhood vaccination. Question 50 was included in the initial questionnaire to specifically capture whether or not parents believe that vaccines their children are administered are effective at preventing disease.

Question 50 was initially adapted from similar questions on the PACV[70], NIS-K and NIK-T[71], and National Poll of Parent's[72] questionnaires. As with the other "confidence" questions, the wording of Question 50 was revised after Round 1 to provide respondents with a three-point confidence scale instead of a binary Yes/No set of answer categories. This question was administered to all respondents in Rounds 1 through 4.

Findings

Nearly all respondents understood this question to be asking whether or not the vaccines their children received decreased their chances of getting sick. The common term that parents used to describe this effect was "lowering the risk." For instance, one mother who answered "Very confident" explained her answer by saying, "Having the vaccine will lower her [daughter's] risk, as long as everything in it works out well."

[70] Question 13
[71] Questions A1
[72] Question KABS11

While most respondents (31 out of 39 in the first four rounds) who received this question answered "Very confident" or "Yes" (in the first version of the question) those who answered using the less positive answer categories did not do so for consistent reasons. Some parents focused in on specific vaccines—most commonly the flu shot—and reasoned that since it sometimes did not protect their children (or them) from the flu, they should answer either "Somewhat…" or "Not at all confident." Others reasoned that it is impossible to prove a negative, and could not possibly be confident that a vaccine was the reason their child did not get sick. For instance, one parent who answered "Not at all confident" explained his answer by saying:

> I know I need to get them, legally and probably for health, but I have no idea if they're actually working…there's no way to know if the reason that someone doesn't get sick is because of their immune system or because of the vaccine.

Other parents noted that even if their child got the vaccine for a specific illness, there was no way to guarantee that they were fully protected. For example, when asked to explain why she answered "Somewhat confident," one mother noted:

> Because it's not 100%. There's no 100% guarantee. I'll use the varicella for example. That's a vaccine I got, but I still got chicken pox and it almost killed me. And my doctor said, "Think of how much worse it could be [without the vaccine], but I couldn't imagine how much worse it could have been because I was going to die.

[Version 1 – Round 1]

Q51: Are you confident that all recommended childhood vaccines benefit your child?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 5]

How confident are you that all recommended childhood vaccines benefit your child?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

Similar to Question 50, Question 51 was included in the initial questionnaire to capture an aspect of respondents' confidence in childhood vaccinations. While Question 50 asks specifically about

the efficacy of vaccines, Question 51 is broader in scope, asking about benefits in general. The decision was made to ask about both of these concepts (efficacy and benefit) to explore whether it is necessary to ask both on a questionnaire or if the constructs they capture overlap.

Question 51 was based on a similar question on the HealthStyles questionnaire[73]. As with the other "confidence" questions, its wording was revised after the first round to provide respondents with a three-point confidence scale instead of a binary Yes/No set of answer categories. It was administered to all respondents in all five rounds, and is included on the final 5-minute question set.

Findings

Question 51 was designed to capture a broader set of benefits than observed in Question 50, and it did so. Across the sample, respondents conceptualized the term "benefit" in a number of ways, including:

- Individual immunity
- Herd immunity and the protection of vulnerable people and groups
- Lowered risk of infection
- Eradication of disease
- General societal benefits, such as productivity
- Potential for better lives with fewer complications

When determining how they would answer this question, most respondents weighed these benefits against what they perceived as vaccines' risks. For instance, one respondent who answered "Very confident" explained that he was thinking about "not getting sick" as the benefit of vaccination. When asked why he answered "Very confident," he said that compared to the risk of getting "soreness or nausea," not getting his son vaccinated was a bigger risk to his health. On the other hand, one mother who answered "Not at all confident" explained that she answered that way because she "…had to weigh the risk to [her daughter] versus the risk to society. But I don't want to do anything that would negatively impact our child." This respondent went on to explain that she and her husband decided to mitigate this risk by not using the standard schedule, but instead spreading out their daughter's shots.

[73] Question VCONFB

A few respondents, particularly ones who answered "Somewhat confident" explained that they did not have the same risk/benefit analysis for all vaccines and instead believed that some vaccines were not necessary. For example, one respondent who answered "Somewhat confident" explained her answer by saying, "I am confident enough to vaccinate her, but not confident that she needed the Hepatitis B shot when she was born. So somewhat [confident]." Likewise, another mother noted that:

> I feel like over the years, some of these things have become somewhat irrelevant. I don't think my child is at risk for getting polio anyways…I'm not going to be the one who doesn't vaccinate her against polio when I guess there's a risk that she's at school with someone who has polio, but it's [a] low [risk].

In general, respondents' answers to Question 51 appeared to better align with their vaccine hesitance than did their answers to Question 50, as illustrated below in Tables 5 and 6 (cells are shaded to make the patterns in the cross tabulation easier to see, with a darker shade indicating a higher percent response within that cell).

Table 5. Percentage of Respondents, by Responses to Questions 35 and 50

	Not at all hesitant	Not that hesitant	Somewhat hesitant	Very hesitant
Very Confident	37	19	11	4
Somewhat Confident	0	4	7	4
Not at all Confident	0	0	7	7

Table 6. Percentage of Respondents, by Responses to Questions 35 and 51

	Not at all hesitant	Not that hesitant	Somewhat hesitant	Very hesitant
Very Confident	47	6	3	0
Somewhat Confident	0	11	19	3
Not at all Confident	0	0	3	8

In Question 50, which asked specifically about protection against diseases, nearly one-half of the respondents who answered "Very confident" indicated that they were something other than "Not at all hesitant" about childhood vaccines. On the other hand, only 16% of respondents who answered "Very confident" to Question 51 answered something other than "Not at all hesitant."

[Version 1 – Round 1]

Q52: Are you confident that the Human papillomavirus, or HPV, vaccine is safe for your child?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that the Human papillomavirus, or HPV, vaccine is safe for your child?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

[Version 1 – Round 1]

Q53: Are you confident that the Human papillomavirus vaccine prevents your child from getting an HPV infection?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that the Human papillomavirus vaccine prevents your child from getting an HPV infection?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

[Version 1 – Round 1]

Q54: Are you confident that the HPV vaccine can benefit your child?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that the HPV vaccine can benefit your child?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

Questions 52, 53, and 54 mirror Questions 49 through 51 above, except that they ask specifically about "the HPV" vaccine instead of "all recommended childhood vaccines." This set of three questions was included on the initial questionnaire in an effort to disentangle the effects that

parents' particular confidence about the HPV vaccine has on their overall confidence in childhood vaccines. Throughout the focus groups, participants noted that they were particularly concerned with "newer" vaccines, meaning vaccines that have been introduced into widespread use since they were children. The HPV vaccine was the most frequently cited of these "new vaccines" (the chickenpox vaccine was also commonly mentioned). In addition to the fact that parents were not sure about the amount of testing that new vaccines such as HPV had been subjected to—thus leading to concerns about safety and efficacy—a number of focus group participants did not appear to understand either the link between HPV and cervical cancer or the fact that males can act as HPV carriers.

Questions 52 through 54 were loosely based on a question on the PACV[74], and were administered to all respondents in Rounds 1 through 4.

Findings

Respondents were split in how they interpreted this set of three questions. While some respondents did focus their answers on the HPV vaccine specifically, many instead continued to think about vaccines generally and did not appear to differentiate between the previous questions that asked about "recommended childhood vaccines" and these three.

Respondents who explicitly thought about HPV while answering this set of questions often did so by comparing the HPV vaccine to other childhood vaccines. For instance, one respondent who answered "Somewhat confident" to Question 53 explained her answer by saying, "Most of these vaccines, people have been getting for decades. But I remember the big push for HPV [when she was in high school]. So, I'm just sort of waiting to see what happens. When the time comes that they recommend that [her daughter] takes it, I'll look into what there is."

As noted above, one of the most commonly cited concerns surrounding HPV was that its relative newness (as compared to other childhood vaccines such as MMR and tetanus) meant that it was not fully tested. However, other respondents believed that the vaccine had been tested enough

[74] Question 13

and were therefore confident in its use on their child. For example, one respondent who answered “Very confident” to Question 53 said:

> I feel strongly about the HPV one. I'm glad that it's actually now approved in boys. I think it's been around long enough…From what I know about HPV, anyone who has sexual intercourse at any point in their life will get it, and what your body does with it, I don’t know, but I think it's important for boys to not spread it as carriers to girls. So yes, my kids will all be getting it.

However, not all respondents directly considered HPV but instead continued thinking about the more general category of recommended childhood vaccines. For instance, one respondent who answered “Yes” to Question 52 said, “I believe in science. If a doctor says to get a vaccine, then it’s been tested and approved.”

Overall, the intent of Questions 52 through 54 was to be able to see how parents’ specific confidence in the HPV vaccine differed from (and thus analytically affected) their confidence in childhood vaccines overall. However, most respondents’ answers across the “recommended childhood vaccine” and HPV sets of questions did not vary. The pairwise comparisons between these two sets of questions (i.e., comparing a respondent’s answer to Question 51 to Question 54) shows that respondents answered the same way to both the “childhood vaccines” and HPV questions 76% of the time. Figure 19 shows these pairwise comparisons for both the HPV and flu (Questions 55 through 57) sets of questions against the overall “recommended childhood vaccines” questions.

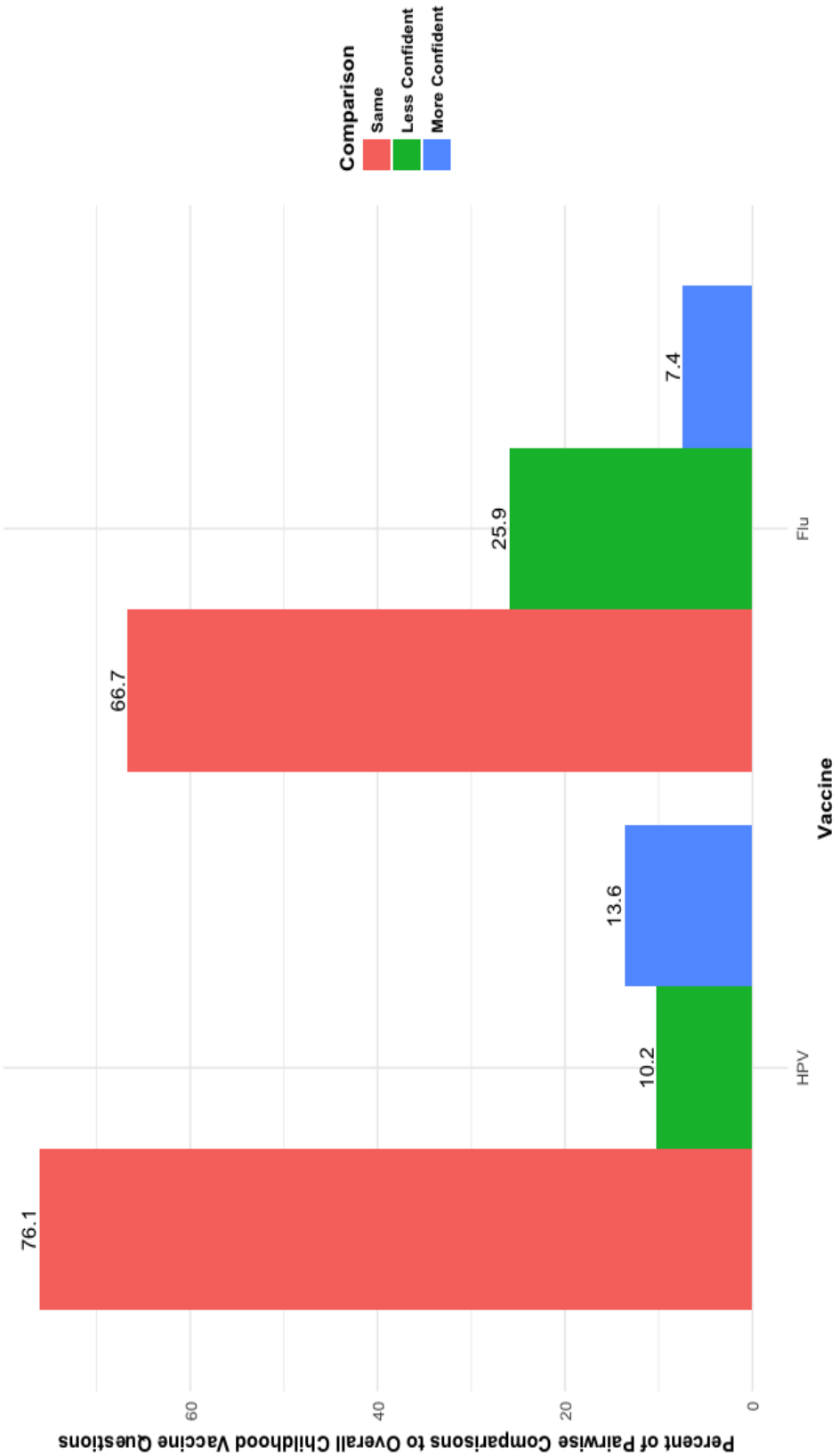


Figure 19: Pairwise Comparisons between Belief in Safety of Childhood Vaccines Generally to HPV and Flu Vaccine

[Version 1 – Round 1]

Q55: Are you confident that the annual flu shot is safe for your child?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that the annual flu shot is safe for your child?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

[Version 1 – Round 1]

Q56: Are you confident that the annual flu shot prevents your child from getting the flu?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that the annual flu shot prevents your child from getting the flu?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

[Version 1 – Round 1]

Q57: Are you confident that the annual flu shot benefits your child?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that the annual flu shot benefits your child?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

Questions 55, 56, and 57 again mirror Questions 49 through 51, but ask about the flu vaccine (stylized in the question as the "flu shot" since that is the vernacular, regardless of the mode of administration) instead of "recommended childhood vaccines." Just as participants' classification of vaccines such as the HPV vaccine as "new" prompted the inclusion of Questions 52 through 54, the fact that parents in the focus groups thought about the flu vaccine in different terms than

other childhood vaccines prompted the inclusion of this set of three questions. The biggest concern that emerged across the focus groups about the flu shot was its efficacy—most respondents said that they did not believe that the vaccine successfully prevented the flu either for themselves or their children. The flu vaccine also stood out in the participants' minds for a few other structural reasons—mainly that it was an annual or recurring vaccine (whereas nearly all the other vaccines they considered to be "childhood vaccines" were administered only once) and that it was a vaccine that they were administered alongside their children. Given this, it became clear during the focus groups (as well as during the cognitive interviews later) that parents incorporated their own experiences with the flu shot into their perceptions of the flu vaccine for their children.

Because of this particular interpretation of the flu vaccine, Questions 55 through 57 were included in the initial questionnaire in an attempt to differentiate how parents thought about the flu vaccine as compared with other childhood vaccines. These questions were adapted from similar questions on the National Internet Flu Survey[75] and the Healthcare Personnel and Flu Vaccine Survey[76] questionnaires. These questions were administered to all respondents in Rounds 1 through 4.

Findings

As compared to the set of HPV questions above (Questions 52 through 54), respondents were more likely to comprehend this set of questions as asking about the flu vaccine specifically and not just childhood vaccines in general. For instance, one mother (who was also a nurse) who answered "Somewhat confident" to Question 55 explained her answer by saying:

> 'Cause the flu shot is a guessing game every year. Even the people who put out the flu shot every year can't tell you with certainty that it's going to prevent your child from getting sick…I got sick with it once. I didn't die, just felt uncomfortable for a week. I've been telling my patients for years [to get the flu shot]. They said "no it makes you sick." I thought they were crazy until I just got sick.

[75] Questions 16 and 18
[76] Question 10

Likewise, another respondent who answered "Very confident" to Question 57 (but only "Somewhat confident" to Question 51 that asked generally about the benefits of all recommended childhood vaccines) explained this discrepancy by saying:
"Because the flu vaccine is unpredictable in its capabilities year-to-year. The flu vaccine is the annual vaccine that represents the best guess. So, of the vaccines, it's the one that I'm least confident will have 100% [efficacy]. But it's greater than 90% effectiveness...Even if it doesn't prevent the flu, studies have shown that receiving the flu vaccination can mitigate at least some of the worst effects. It's a balancing act. But I'm confident that they should get it."

Nonetheless, when looking across the pairwise comparisons of each of these three flu vaccine confidence questions with their equivalent in the overall childhood vaccine confidence set, most respondents still reported the same answer across the pairs. As shown in Figure 19, 66.7% of the respondents' answers were the same to both the overall childhood vaccine and flu vaccine questions.

[Version 1 – Round 1]

Q58: Overall, are you confident that vaccines you get for your child will prevent diseases?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 5]

Overall, how confident are you that vaccines lower your child's risk of getting diseases?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

Question 58, much like Question 50 above, was included in an attempt to capture parents' confidence in the overall efficacy of childhood vaccines. However, while Question 50 asked about whether vaccines "protect" children against diseases, Question 58 is framed in terms of risk (in Version 2). Both questions were included on the initial questionnaire to determine the optimal way of asking parents about efficacy.

Question 58 was modified in two ways between Versions 1 and 2. Like the other "confidence" questions, the binary Yes/No answer categories were replaced with a three-point confidence scale after Round 1. Additionally, the core question text was changed from asking about whether vaccines "prevent diseases" to whether they "lower the risk" of diseases. This change was made due to the fact that in the first round of testing, a few respondents indicated that they did not know whether or not vaccines prevented diseases, since in the words of one father, "It's impossible to prove a negative." The wording was altered to emphasize the attitudinal nature of this question.

Question 58 was adapted from a similar question on both the NIS-K and NIS-Teen[77], and was administered to all respondents in all five rounds of cognitive testing. Additionally, it is included on the final 5-minute question set.

Findings

Respondents understood Version 2 of Question 58 to be asking about whether or not they thought that, as a set, childhood vaccines were effective at decreasing their children's risk of getting sick. Respondents were also consistent in how they determined their answer to this question—with respondents who answered "Very Confident" expressing that all childhood vaccines work, at least in some way, to reduce risk of disease; whereas respondents who answered "Somewhat…" or "Not at all Confident" noted that some vaccines did not work as intended.

For example, one respondent who answered "Somewhat confident" explained her answer by saying, "It depends on the individual. If they are strong, the vaccine might help their immune system. If they're weak, the vaccine can weaken it further." Other respondents considered the efficacy of individual vaccines when answering either "Somewhat" or "Not at all Confident." For instance, one father answered "Somewhat confident" and when asked to explain noted that he was not convinced about the efficacy (or necessity) or the HPV vaccine. When asked how he would respond if he was thinking about childhood vaccines *except* for the HPV one, he said he

[77] Questions A3

would change his response to "Very confident," but since he thought that the question included HPV, he answered with the lower confidence rating.

[Version 1 – Round 1]

Q59: Are you confident that childhood vaccines protect the general public from severe diseases?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that childhood vaccines protect the general public from severe diseases?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

Question 59 was included on the initial questionnaire in an attempt to capture a specific aspect of the efficacy of childhood vaccines—their ability to protect the public through herd immunity. The focus groups revealed that most parents generally understood the concept behind herd immunity—that a population is protected from a disease if enough people are immunized against it—even if they did not know the specific term.

Question 59 was adapted from similar questions on the PACV[78] and the National Poll of Parents[79]. Like the other "confidence" questions, it was revised after the first round by changing the binary Yes/No answer categories to a three-point confidence scale. This question was administered to all respondents in Rounds 1 through 4.

Findings

Respondents generally understood this question to be asking about whether or not they were confident (or, in Version 2, how confident they were) that childhood vaccinations lead to herd

[78] Question 8
[79] Question KABS12

immunity. For example, one mother who answered "Yes" to Version 1 of the question explained her response by simply saying, "Herd immunity is a thing."

Others did not specifically mention the term "herd immunity," but reasoned that the relative lack of outbreaks of vaccine preventable disease indicated that something was working. For instance, one respondent who answered "Very confident" noted: "I say that because that's the whole point. That's the whole point of this. So, everyone isn't just running around with these preventable diseases…Because I'm not seeing these mass cases of measles and mumps and polio...so even though I don't know the studies and the research, I do know those outbreaks aren't happening. So, they must be working, something's working!"

The few respondents who did not answer "Yes" or "Very confident" (only 8 of the 50 respondents) all indicated that they did not know enough to be sure. For example, one father who answered "Somewhat confident" explained that "because there isn't a control case," he can't be completely sure that the vaccines are working.

Q60: Do you believe that serious reactions from childhood vaccines are rare?

1. **Yes**
2. **No**

Question Design and Background

Question 60 was the first in a series of binary Yes/No questions asking directly about respondents' beliefs and attitudes about aspects of, and concerns about, immunization. As compared to the "concern" questions (Questions 38 through 47), these "belief" questions (Questions 60 through 70) do not ask the respondents to link their attitudes with their vaccination behaviors. Question 60 for instance asks about serious side effects, but unlike Question 45 above, does not attempt to link how concerns about serious reactions to vaccines affected vaccination behavior.

As mentioned throughout this report, the risk of their child having a serious side effect or reaction to a vaccination is a frequently cited concern by parents. This question attempts to

capture whether or not respondents believe such side effects or reactions are uncommon. This question was written *de novo* for the initial questionnaire, and was administered to all respondents in Rounds 1 through 4.

Findings

All but five of the respondents who received this question answered "Yes." Respondents largely understood the phrase "serious reactions" to be referring to life-threatening side effects. However, the few respondents who answered this question "No" included things such as fevers and rashes. For instance, one father explained his "No" response by saying that he was thinking about "a fever, that's not too rare. My daughter [has] had fevers after getting shots."

[Version 1 – Round 1]

Q61: Do you believe that the benefits recommended vaccines provide your child outweigh their risks?

1. **Yes**
2. **No**

[Version 2 – Rounds 2 through 4]

How confident are you that the benefits of vaccines outweigh their risks?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

Throughout the focus groups and cognitive interviews, parents repeatedly mentioned that they had to do a risk/benefit analysis when deciding whether or not to vaccinate their children. In short, parents had to weigh the risks of vaccine side effects (both common and serious ones) with what they perceived as the benefits of vaccination. In general, parents who believed that the benefits of vaccinations outweighed their risks appeared to be less hesitant (and therefore more accepting) of childhood vaccines, and vice versa. Question 61 was originally designed to capture this binary. However, analysis of the results of Rounds 1 through 3 revealed that respondents felt restricted by this binary choice. In fact, across the 29 respondents who received Version 1 of this question in the first three rounds of testing, only one parent answered "No." This lack of variation did not match up with the complex discussions surrounding the risk/benefit analysis

that parents discussed during the focus groups or the probing of Version 1 during the cognitive interviews revealed. As a result, this question was revised for Round 4 from a Yes/No binary "belief" question to a three-point confidence scale. This change led to more variation in respondents' replies, with 10 responding "Very confident," 8 answering "Somewhat confident" and 3 of the 21 respondents in the final two rounds answering "Not at all confident."

The original version of this question was designed based on a similar question on Pew's American Trends Panel in 2016[80]. This question was administered to all respondents in all five rounds, and is included on the final 3- and 5-minute question sets.

Findings

Across both versions of the question, respondents universally understood this question to be asking about how they weighed the benefits of childhood vaccination against its perceived risks. For example, one respondent who received Version 1 and answered "Yes" explicitly mentioned the risk/benefit calculation she had to make:

> I think of vaccinating my children in terms of risks versus benefits. Just things like common sense. Life expectancy post-vaccination error and things like that. Obviously, it works. I would never want to see my child sick or die from something that could have been protected [against]. So, the benefits far outweigh the risks. But I acknowledge that there are still some risks.

Likewise, a respondent who answered "Somewhat confident" in Version 2 of the question noted that he was thinking that, "Some vaccines work and they prevent diseases, but others may not. Everybody is different, so maybe it won't work for someone and they'll still get sick."

Variation did emerge across the two versions in how respondents judged and answered Question 61. With their response options restricted to the binary Yes/No in Version 1, respondents appeared to have a higher bar for providing a negative response. As noted above, all but one respondent who received the first version of the question answered "Yes." However, most of these respondents mentioned concerns and perceived risks of childhood vaccination during probing. For example, when asked to explain her "Yes" response, one mother said, "Well the

[80] Question BIO34. See report at http://assets.pewresearch.org/wp-content/uploads/sites/14/2017/02/01172718/PS_2017.02.02_Vaccines_FINAL.pdf

benefit is that she [her daughter] will have a stronger immune system and be healthier. The risks are that she may feel bad and have some bad reactions. But that would be unusual."

In Version 2, respondents who answered "Very confident" rarely mentioned the risks, and instead focused their explanations only on the benefits of childhood vaccines. For instance, another mother noted that she arrived at her "Very confident" response because, "Getting the disease is a lot more trouble than getting the vaccine!" Respondents who answered "Somewhat confident" and "Not at all confident" were more likely to bring up concerns and perceived risks. For example, one father who answered "Somewhat confident" said:

> I don't like foreign things in my child's body. You just don't know, there could be side effects. But vaccine is medicine. The benefits of the vaccine—not getting the disease—outweigh the risks of the side effects.

Q62: Do you believe that recommended vaccines give your child the best protection from serious diseases?

1. Yes
2. No

Question Design and Background

Question 62 was written *de novo* for inclusion in the initial questionnaire. It was designed in an effort to capture respondents' beliefs about childhood vaccination in regards to serious diseases. This question was only administered in Round 1.

Findings

Respondents who received Question 62 were unsure how to judge their response, with many commenting on the phrase "the best." For instance, the immediate reaction of one respondent who answered "No" was to ask the interviewer, "The best? Well, I don't know. That word makes me cautious." Another respondent, who answered "Don't know," reacted to the question by asking, "Compared to what?"

Q63: Do you believe that vaccines are adequately tested for safety before they are administered to your child?

1. **Yes**
2. **No**

Question Design and Background

One point that many of the vaccine-hesitant parents returned to throughout the focus groups held at NCHS was that they could not be completely confident in the safety of childhood vaccines because they did not believe that they were tested rigorously. Some parents explained that they believed this because new vaccines appear more frequently than they remember from their own childhood and early adulthood, while others tied this lack of faith in the safety testing to distrust of the government and/or pharmaceutical companies. Question 63 was designed to capture this belief.

This question was based on a similar one on the National Poll of Parents questionnaire[81], and was administered to all respondents in Rounds 1 through 5. This question is included on the final 5-minute question set.

Findings

Respondents generally understood this question to be asking about their opinion about the rigor of vaccine testing. Respondents who answered "Yes" believed that the testing and regulatory processes in place were adequate, whereas respondents who answered "No" thought they were lacking. For instance, when asked to explain her "No" answer, one respondent said, "There's only so much you can do with in terms of human testing. With those limitations, it's not realistic to test on a whole bunch of kids and see what happens to them."

Three respondents answered the question "Don't know," with all explaining that they were not sure what testing procedures or results were required, and whether the ones that were required were sufficient. For example, one parent explained her "Don't know" response by saying:

> I have the same feeling about all medications. I'm constantly hearing stories about drugs not being tested enough or drugs that take too long to test. You never hear stories about how drugs are tested perfectly. I'm just wondering if the testing is

[81] Question KABS 13_2s

> being done with the right priorities in mind…they're [the pharmaceutical companies] doing it to make money.

Another respondent simply explained his "Don't know" answer by noting that, "I simply don't know what good medical testing is."

Q64: Do you believe that vaccines strengthen your child's immune system?

1. Yes
2. No

Question Design and Background

Question 64 was designed *de novo* for the initial questionnaire, and was intended to capture parents' beliefs in the efficacy of childhood vaccines and their overall impact on children's immune systems.

Question 64 was administered to all respondents in Rounds 1 through 4.

Findings

Two divergent interpretations of this question emerged across the four rounds of respondents who received Question 64. Most respondents, particularly those who answered "Yes," answered the question based on whether or not they thought that vaccines worked as they were designed—that is to supplement a body's immune system by prompting it to create antibodies. For example, one father who answered "Yes" noted that "They get the vaccine, they develop antibodies to ward off the disease. That strengthens the immune system." Another respondent simply explained her "Yes" response by saying, "As far as I know, that's what they're designed to do."

On the other hand, most respondents who answered "No" interpreted the question to be asking about whether or not they believed that childhood vaccines improved their child's immune system, specifically. In other words, when answering this question, they were considering whether or not they believed that their child's immune system *needed to be strengthened*. For instance, one mother who answered "No" explained her answer by saying "His [her son's] immune system is already very strong." Likewise, another respondent explained his "No" answer

by saying, “In general yes, but not for [his son].” When asked why, this father said that his son did not need the extra help, and that his immune system was strong to begin with since he did not get sick very often.

Q65: Do you believe that most vaccine side effects are minor, such as soreness at the spot where the shot was given or a low-grade fever?

1. **Yes**
2. **No**

Question Design and Background

Question 65 was included in the initial questionnaire in an effort to capture whether or not respondents believed the fact that most side effects of vaccinations are minor. During the focus groups, the relationship between whether or not parents trusted the materials and messages they were provided by the medical community about childhood vaccines and their overall views on childhood vaccination became apparent. Question 65 was written *de novo* in an effort to capture the first part of this equation.

This question was administered to all respondents in Rounds 1 through 4.

Findings

Respondents interpreted the term “minor” in two ways and each of these interpretations produced only a single survey response, as illustrated below:

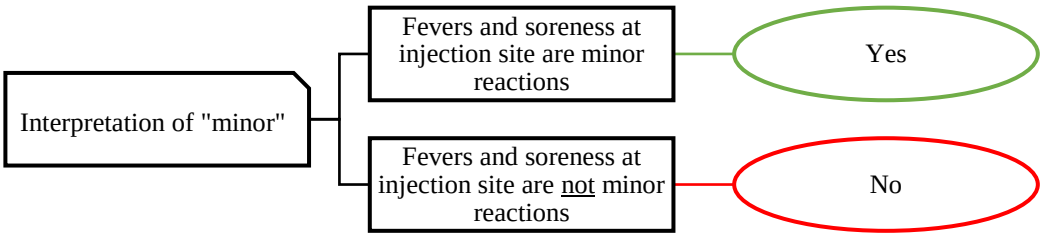


Figure 20. Patterns of Interpretation and Associated Survey Answers for Question 65

Nearly all respondents understood this question to be asking about whether or not they believed that the most common side effects of childhood vaccinations were reactions such as fevers and lethargy, which most respondents considered to be “minor.” All but 3 of the 39 respondents who received this question answered “Yes,” and by and large they interpreted “minor” as the question

text suggested. For example, one parent who answered "Yes" said her daughter has only ever had a "low-level fever after getting shots, and it's usually gone the next day."

However, the three respondents who answered "No" disagreed that fevers—even low-level ones—should count as "minor" side effects. Instead, they answered "No," arguing that fevers are serious reactions. For instance, one father who answered "No" explained his response by saying, "A fever is not minor! She's had a fever, so 'no.'"

Q66: Do you believe that childhood vaccines prevent potentially deadly diseases?

1. **Yes**
2. **No**

Question Design and Background

Question 66 was written *de novo* for the initial questionnaire in an attempt to capture respondents' beliefs about the efficacy of vaccines against serious illnesses. It was administered to all respondents in Rounds 1 through 4.

Findings

Of the 39 respondents who received this question, all but 6 responded "Yes." All respondents understood the question to be asking whether or not they believed that vaccines were generally effective at preventing serious diseases.

Q67: Do you believe that there is a link between recommended childhood vaccines and the development of conditions such as autism?

1. **Yes**
2. **No**

Question Design and Background

Like Question 46 ("Did concerns about your child developing Autism or an Autism Spectrum Disorder impact your decision to get [him/her] vaccinated?"), Question 67 was included in the initial questionnaire to capture parents' attitudes surrounding the erroneous link between childhood vaccines and Autism Spectrum Disorder. As noted above, even though no evidence

exists to show this link exists, research into childhood vaccine hesitance (Brown et al 2010) suggests that it remains a salient factor for some parents. The focus groups conducted by NCHS bore this out, with a number of parents mentioning their concern that childhood vaccines may cause their child to develop autism.

This question was written *de novo* for the initial questionnaire, and was administered to all respondents in all five rounds. Question 67 is also included on the final 5-minute short set of questions.

Findings

Respondents universally understood Question 67 to be asking about their belief that childhood vaccines may cause developmental conditions such as Autism Spectrum Disorder. For example, one respondent who answered "Yes" explained her answer by saying:

> After [her son] got his vaccines, I saw really significant changes in his behavior. The research I did said there might be a connection. I know it's not a definitive link, but that's because people don't want to make a definitive link because they'd have to change the protocol…We can't say exactly what's happening, but I know his 12-month visit was normal, but after that…you look at what's changed and you start to research, and then you see it's not just me.

Similarly, a father who answered "No" noted about the supposed link that, "I think it's a myth. Large studies of tens of thousands of people [have been completed] and no link was ever shown between vaccines and autism."

As compared with Question 46, which attempts to tie opinion and behavior, respondents' answers to this question appear to be more in line with their overall hesitancy towards childhood vaccines. Tables 7 and 8 below show the hesitancy (Question 35 above, collapsed into two categories here) within the responses to Question 46 and 67, respectively:

Table 7. Percentage of Respondents' Hesitancy towards Childhood Vaccines (Question 35), by Their Responses to Question 46

	Hesitant	**Not Hesitant**
Yes	60.0	40.0
No	25.9	74.1
Don't Know	0.0	100.0

Table 8. Percentage of Respondents' Hesitancy towards Childhood Vaccines (Question 35), by Their Responses to Question 67

	Hesitant	Not Hesitant
Yes	75.0	25.0
No	22.6	77.4
Don't Know	16.7	83.3

One would expect respondents who believed in a link between vaccines and autism to be more hesitant towards childhood vaccines; Question 67 appears to do a better job of capturing this trend than Question 46 based on the higher percentage of hesitant parents who responded "yes".

Q68: Do you believe that getting your child vaccinated helps protect others from getting disease?

1. Yes
2. No

Question Design and Background

Similar to Question 59 above, Question 68 was included in the initial questionnaire in an effort to capture respondents' opinions on the specific aspect of the efficacy of vaccines known as herd immunity, or the idea that if enough of the population is inoculated against a particular disease the part of the population that has not been vaccinated will be protected. As noted above, the focus groups revealed that most parents were familiar with this concept, even if they did not use the specific phrase "herd immunity." Both Questions 59 and 68 were included on the initial questionnaire to see whether phrasing this attitudinal question as a confidence or a belief question, respectively, would better capture respondents' opinions.

This question was adapted from a similar question on the HealthStyles[82] questionnaire, and was administered to all respondents in Rounds 1 through 5. It is included on the final 5-minute question set.

Findings

Respondents appeared to universally understand this question to be asking about this intended construct—whether or not they believed that getting their own child vaccinated helped prevent

[82] Question VPRTCOM

the disease among others. For example, one mother who answered "Yes" said, "Herd immunity is real!" Likewise, another respondent explained her affirmative response in detail, by saying:

> I guess I've always thought about it like if your child is around…by having her vaccinated, she's not getting certain diseases. However, there are babies that are younger than her who haven't had certain vax yet. So, if she wasn't to get vaccinated and contract something, it could get passed on to a child who hasn't had all their vax yet. So that's how I see it...so it's the same reason I didn't take [his daughter] out into crowds until she had more of her inoculations.

Respondents who answered the question "No" also understood the question in the same way as those who answered "Yes," but simply did not believe that others were protected if their child received a vaccine. For instance, when asked to explain his response, one father who answered "No" said, "Other people are still going to get it, whether my son's vaccinated or not," noting that vaccines "lower his risk, but not others'." Similarly, another respondent who answered "No" explained that, in her mind, "No, that's not how vaccines work."

Q69: Do you believe that parents have an obligation to vaccinate their children?

1. Yes
2. No

Question Design and Background

While a lot of the existing research on childhood vaccine hesitancy indicates that many parents choose to vaccinate their kids because of the threat of school and daycare requirements, the focus groups revealed that many pro-vaccine parents thought about vaccinations as something they should do (as opposed to something they *must* do). Consider the following conversation from one of the focus group discussions held at NCHS:

> Moderator: Have you looked at what your school district requires?
>
> Participant 1: There's a list, I think it's the same as the doctor's list. But that's not why I do it. I mean, my job as a parent is to make good decisions that will help my kid thrive. And vaccines will protect her. So, it's necessary.
>
> Participant 2: Right, an obligation. Like you need to do right by your children.
>
> Participant 1: That's right. You're the adult, so you need to protect them.

Question 69 was written *de novo* in an attempt to capture this attitude. This question was administered to respondents across all five rounds of testing, and is included on the final 5-minute question set.

Findings

In general, while respondents understood this question to be asking about whether or not they, as parents, had to get their child vaccinated, they conceptualized this obligation in two ways: a moral obligation or a legal obligation. How respondents understood the term "obligation" appeared to directly relate to how they answered the question, as illustrated in the schema below:

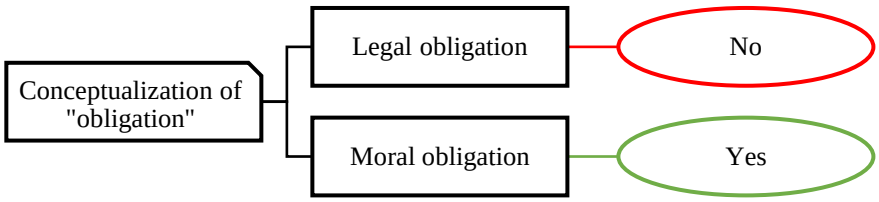


Figure 21. Patterns of Interpretation of the term "Obligation" in Question 69 and Associated Survey Responses

All respondents who answered the question "No" explained that they based their answer on whether or not there should be a legal requirement or obligation for a parent to vaccinate their children. Upon further probing, most of these parents indicated that children should be vaccinated, but that it should also be a parent's right to make their own medical decisions. For example, one parent explained her "No" response by saying:

> Well, I know I'm cool with it. Because I grew up here, I was raised in America. But I don't want to infringe on someone else's religious beliefs, or at least I don't feel comfortable doing that. And at the end of the day, if they don't want to vaccinate their child, well, you know: my child is vaccinated. So, if their child gets sick, that shouldn't matter to my child because she's vaccinated.

Likewise, another respondent who answered "No" said, "There should be exemptions for religious reasons. Many religions believe that the body should heal itself." Other respondents who answered "No" indicated that specific vaccines should not be required. For instance, one mother said "No" and went on to note, "I believe we have the right to opt in and opt out of certain vaccinations. Gardasil and flu should be the ones to be optional."

On the other hand, most respondents who answered "Yes" all thought about the word "obligation" as a moral requirement that they should do as part of their role as parents. One parent simply explained her affirmative answer by saying:

> Like morally, you're not doing everything you can to protect the child if you don't do it. Like if your main job as a parent is to provide a safe space for your kid, you're skipping a huge thing if you don't.

Another respondent who answered "Yes" said that she answered that way thinking, "To vaccinate is the right thing to do. I don't know if it's selfish, but they're [people who don't vaccinate] risking both their kid and other kids." This idea that the moral responsibility extended to both their own children and others who cannot be vaccinated was common. For instance, when explaining her "Yes" response, a mother said:

> I think that if you're sending your child to a public school, you should vaccinate your child if that's what's required. I think that if you choose not to vax your child and you send them to school, and there's another kid in that class who can't get a vaccine, you just put their lives in your hands in addition to your own child.

Q70: Do you believe that your child's immune system can handle several vaccines at one doctor's visit?

1. **Yes**
2. **No**

Question Design and Background

One of the common concerns that parents brought up throughout both focus groups and the cognitive interviews was that children, especially infants, are given too many vaccines at once. For instance, at the 2-month checkup, infants can receive five or six vaccines if they follow the standard CDC schedule[83]. While some parents brought up the idea that their child would be in too much pain (see Question 41) or that the volume of medicine was too great for their small bodies (see Question 39), the most common concern was over how their children's immune systems would react to such a large stimulus. Question 70 is very similar to Question 38 above, but asked as a Yes/No belief question instead of a Yes/No concern question.

[83] https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html

This question was based on a similar one on the HealthStyles questionnaire[84], and was administered to all respondents in Rounds 1 through 4.

Findings

Respondents universally understood this question to be asking whether or not they believed that their child's body and immune system could handle receiving several vaccines at once. For instance, one respondent who answered "Yes" explained, "She has, so she can!", while another said, "I do believe that she can handle several—several to me is three to four…Because she's done it, because I've seen it done to other people, to other children." This was a common interpretation: respondents reasoned that since their children had already received multiple vaccines at once, their bodies could obviously handle the load—even if they did not like it.

Q71: Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]

1. **Your Child's Primary Care Doctor**
2. **Your Primary Care Doctor**
3. **Other Doctors Besides Your or Your Child's Primary Care Doctors**
4. **Nurses**
5. **Other Health Care Providers**
6. **Your Parents or Grandparents**
7. **Your Spouse or Partner**
8. **Your Peers**
9. **The Centers for Disease Control and Prevention (CDC) website**
10. **Your Local School System**
11. **Web Sites Such as WebMD**
12. **Parents' Message Boards and Other Similar Online Communities**
13. **The Centers for Disease Control and Prevention**
14. **Your Local Health Department**

Q72: Which of the following sources do you trust when making vaccination decisions for your child? [SELECT ALL THAT APPLY]

1. **Your Child's Primary Care Doctor**
2. **Your Primary Care Doctor**
3. **Other Doctors Besides Your or Your Child's Primary Care Doctors**
4. **Nurses**

[84] Question VCONC

Q71: Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]

5. **Other Health Care Providers**
6. **Your Parents or Grandparents**
7. **Your Spouse or Partner**
8. **Your Peers**
9. **The Centers for Disease Control and Prevention (CDC) website**
10. **Your Local School System**
11. **Web Sites Such as WebMD**
12. **Parents' Message Boards and Other Similar Online Communities**
13. **The Centers for Disease Control and Prevention**
14. **Your Local Health Department**

Question Design and Background

Some of the most informative discussions in the focus groups centered upon the sources of information that parents both trusted and distrusted when making vaccination decisions. In general, parents who were favorable towards childhood vaccinations reported trusting more "institutional" sources, such as the CDC and doctors and other health professionals in general; parents who were hesitant towards vaccines tended to trust personal contacts and websites more than health professionals and the government.

This overlapping set of trusted and distrusted sources became clearer when analyzing the freelist data provided by the focus group participants. Figures 26 and 27 (in Appendix B below) show the salience of trusted and distrusted sources of information about childhood vaccines that was obtained from the freelisting exercise in the focus groups (salience, measured here with Smith's S[85], is a metric that combines both rank and frequency of each item across all the participants' freelists). Both the freelist analysis and the discussions themselves indicated that vaccine-hesitant parents distrusted medical authorities when making their decisions (and that vaccine-accepting or neutral parents trusted these same authorities).

Given these findings, Questions 71 and 72 were designed *de novo* for the initial questionnaire in an attempt to capture respondents' trusted and distrusted sources.

[85] Smith, J.J. and S.P. Borgatti. 1998. "Salience counts—and so does accuracy: Correcting and updating a measure for freelist-item salience." *Journal of Linguistic Anthropology* 7(2): 208-209.

Findings

Questions 71 and 72 were not probed explicitly, and instead were included in the questionnaire to facilitate conversations around respondents' trusted and distrusted sources of information about childhood vaccinations. No cognitive findings are available.

Q73: Is information that your child's doctors or other health care professionals provide you about vaccines credible and trustworthy?

1. **Yes**
2. **No**

Q74: Is information that federal government agencies, such as the CDC, releases about vaccines and immunizations credible and trustworthy?

1. **Yes**
2. **No**

Question Design and Background

Given that the overall intent of the final question sets will be to assist with CDC and HHS' messaging around childhood vaccines, questions specifically asking about the trustworthiness of these two particular sources were included in the initial questionnaire. Both Questions 73 and 74 were adapted from a similar question on the PACV[86], and were asked of all respondents in Rounds 1 through 4.

Findings

Both Questions 73 and 74 were interpreted similarly, with respondents basing their decisions on whether either their doctor or the CDC was trustworthy on a common set of criteria. Figure 22 below illustrates the schema respondents used to interpret this question:

[86] Question 15

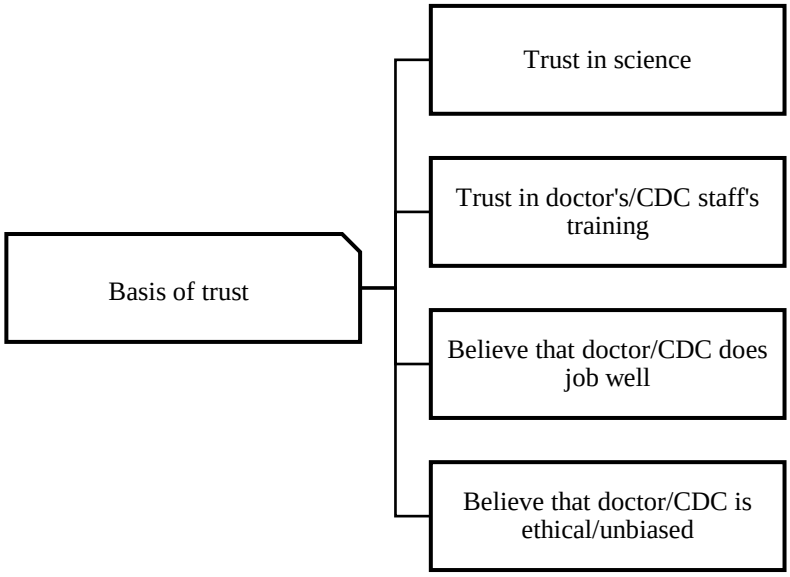


Figure 22. Patterns of Interpretation for Question 73

By and large, three of these interpretations—trust in science, trust in the doctor or staff's training, and belief that they do their job well—stem from the idea that the parents consider doctors (and CDC, which most respondents appear to believe is largely staffed by doctors) have the requisite expertise to both do their jobs and provide good advice. For instance, one respondent who answered "Yes" to Question 73 explained her answer by saying:

> I have a lot of trust in my daughter's physician and his clinic. I do believe they want to do what's best for the children they treat. I do believe that the CDC has put forth guidelines for physicians to follow and those recommended guidelines are tried and true. At least for what physicians should recommend for their patients.

Similarly, another father said that he trusted his doctor and the CDC, and explained:

> Generally, a medical professional or a pediatrician, I would take their opinion over anyone else…I view information from CDC on par with a pediatrician. I assume that's where the pediatrician is getting his information.

A few other respondents noted that they trusted their doctor or the CDC because they saw them as unbiased or ethical individuals or institutions. In doing so, these respondents tended to compare (either implicitly or explicitly) their doctors and the CDC to entities they considered suspect, such as the FDA and pharmaceutical companies. For example, one respondent who answered "Yes" to Question 74 explained her answer, saying:

> I trust that CDC has the most up to date and accurate info because it's a government agency…they would have the greatest access to data. They provide unbiased facts—not for the benefit of or focused on a particular group.

While both of these questions were interpreted consistently across the cognitive interviewing sample, they did not differentiate between respondents who were hesitant toward or confident in childhood vaccines: only one respondent answered "No" to either question.

Q75: Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from my doctor than from other sources

1. **Agree**
2. **Disagree**
3. **Neither Agree or Disagree**

Q76: Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from the Centers for Disease Control and Prevention (CDC) than from other sources

1. **Agree**
2. **Disagree**
3. **Neither Agree or Disagree**

Q77: Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from my family than from other sources.

1. **Agree**
2. **Disagree**
3. **Neither Agree or Disagree**

Q78: Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from something I've read than from other sources.

1. **Agree**
2. **Disagree**
3. **Neither Agree or Disagree**

<u>Question Design and Background</u>

As mentioned above, throughout the focus groups, non-vaccine hesitant participants kept returning to the fact that they trusted their children's doctor for medical advice, while vaccine hesitant participants indicated that their children's' doctors were not their primary source of information—instead relying on sources such as family and friends. Questions 75 through 78 were designed *de novo* in an attempt to capture respondents' ranking of their sources of information about childhood vaccines. These questions were administered to respondents in Round 1 only.

Findings

Nearly all of the respondents who received this series of questions in Round 1 expressed difficulty comprehending what was being asked. Specifically, respondents were not sure what to include in the term "other sources," particularly in Questions 76, 77, and 78, where they were not sure whether to exclude sources they had already been asked about. For example, explaining his confusion to Question 76 (which asked respondents to compare their trust in the CDC to all other sources of information), one respondent said:

> With the exclusion of my doctor [which was asked about in Question75]?...I mean, I guess I'll say yes, because I assume my doctor gets information from the CDC? But it's weird to answer "yes" to both of these.

This was a common refrain, with respondents asking to go back to revisit previous questions after they had been administered the full set of four questions as they did not believe they could logically answer "Yes" to more than one. Other respondents noted this logical issue, but did not request to revisit their previous answers, leaving multiple "Yes" responses. Due to this overwhelming confusion, these questions were dropped after Round 1.

Q79: Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I trust recommended childhood vaccines that have been in use a long time more than I trust those that have recently become available.

1. **Agree**
2. **Disagree**
3. **Neither Agree or Disagree**

Question Design and Background

One of the major concerns that participants in the NCHS focus groups expressed was that drug companies, and to a lesser extent the medical profession and the government, were using their children as "test subjects" or "guinea pigs" to validate the effectiveness and safety of vaccines. As might be expected, this critique was largely limited to "newer" vaccines—particularly those that had come onto the market since the parent themselves received their own childhood vaccines.

Given this sentiment, Question 79 was adapted from a similar question on the NIS' Parental Knowledge and Experiences Module (PKM)[87]. It was included in an attempt to capture whether respondents trusted older (and therefore safe and "tested") vaccines more than newer ones. This question was administered to all respondents in the first four rounds of cognitive testing.

Findings

Respondents all understood this question to be asking about whether they trusted childhood vaccines that had been on the market for a long time more than those that were newer to the market. In practice, respondents appeared to conceptualize these classes of vaccines by thinking about some common exemplars—for older vaccines, most parents thought about vaccines they had been administered themselves as children, such as the MMR vaccine; for newer vaccines parents exclusively focused on the chicken pox and the HPV vaccines in their narratives.

Respondents who answered "Agree" to Question 79 nearly all based their answers on the judgment that vaccines that have been on the market longer have more evidence of their safety and effectiveness. In particular, many respondents appeared to argue that these vaccines' long track record made them feel comfortable, and that newer vaccines that do not have this evidence base cannot be trusted to the same extent. For instance, one respondent—who noted that she was going to get her daughter vaccinated no matter what—explained that all other things being equal, she would prefer older vaccines, saying, "The older ones have been happening for decades, and nothing crazy has happened that [led to them being] recalled. Versus HPV, it's new, so I don't know." Another respondent used very similar reasoning while explaining her "Agree" response:

[87] Question 9

> I agree, but I wouldn't hesitate to give them to my child though…It's like any drug or vaccine. First you approve it, then FDA has accepted and reviewed it safe. Then there are things we don't know when we approve things. So, when they are out a little longer we get a bigger safety profile on drugs and vaccines both. We learn about things after some years. But that doesn't stop me if it's been approved, I'm going to use it.

Beyond this reasoning based on the existence of an extensive evidence base for the older vaccines, a few other parents argued that newer vaccines are not tested on humans before being introduced to the market. However, these parents believed that older vaccines were in fact tested on humans, making them more trustworthy. For instance, one respondent explaining her "Agree" answer spoke about older vaccines (which she called "regular vaccines") and said that:

> They've been around a long time. The limitations on human testing with something that is new, and they are still working out the kinks like HPV... It came out when my niece was school age, so there's no way to really know long-term effects like with regular vaccines with years and years of data.

(It is important to note that this view of human testing is not factual—the current vaccine testing and approval process does indeed include human clinical trials[88]. Nonetheless, this view emerged across participants in both the focus groups and the cognitive interviews and clearly shapes how some parents view newer vaccines.)

Respondents who answered either "Disagree" or "Neither…" based their answers on one of two patterns: either believing that there is no difference between the trustworthiness of newer and older vaccines, or believing that newer vaccines are actually more trustworthy than older ones because they are based on more modern science than older ones.

While this question appeared to capture the construct for which it was designed, it was not included in any of the final short sets of questions as it did not differentiate between respondents who were and who were not hesitant towards childhood vaccines as well as other items did. Specifically, while all but one of the respondents who were vaccine hesitant that received this question answered "Agree," parents who were confident in vaccines split their answers between "Agree" and the other two response categories.

[88] https://www.cdc.gov/vaccines/basics/test-approve.html

[Version 1 – Rounds 1 through 3]

Q80: If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. **Mostly supportive of vaccines**
2. **Neutral toward vaccines**
3. **Mostly unsupportive of vaccines**
4. **I do not discuss vaccines with friends and family**

[Version 2 – Round 4]

If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. **Mostly supportive**
2. **Mostly neutral**
3. **Mostly unsupportive**
4. **Mixed – that is, both supportive and unsupportive of vaccines**
5. **I do not discuss vaccines with friends and family]**

[Version 3 – Round 5]

If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. **Mostly positive**
2. **Mostly negative**
3. **Mixed—that is, both positive and negative**
4. **Mostly Neutral**
5. **I do not discuss vaccines with friends and family]**

Question Design and Background

The focus groups and cognitive interviews reiterated that, in addition to pediatricians, parents are also strongly influenced by their social network's view of vaccines—particularly family and friends with whom they have conversations in real life (as opposed to simply communicating online). Question 80 was designed to capture the valence of the attitudes towards vaccines that parents encounter in these conversations.

The question was based on a similar question from the National Poll of Parents questionnaire[89]. The first version of the question (administered in Rounds 1 through 3) did not include a "neutral" answer category; this was revised in Round 4. The question was further revised between Rounds 4 and 5 to use the terms "positive" and "negative" instead of "supportive" and "unsupportive"—the latter of which appeared to cause some respondents confusion about the overall purpose of

[89] Question ADVICE3A

the question. Version 3 of Question 80, which was tested in Round 5, is included on the final 5- and 3-minute question sets.

Findings

Respondents largely understood this question to be asking about the overall tenor of the discussions they have had with friends and family about childhood vaccines. Two issues emerged across the various versions of the question that were addressed with slight edits.

The "averaging" issue: In Version 1 of Question 80, three substantive answer categories were provided (supportive, not supportive, and neutral), in addition to a forth category that indicated that a respondent had not had such discussions). This set of answer categories confused some respondents who explained that they had a relatively even distribution of vaccine-supportive and vaccine-unsupportive discussions.

Some of these respondents felt forced into one of the polar answer categories. For instance, one mother in the second round answered "supportive," and explained that "I guess they're mostly supportive. I work with a few people who are anti-vax, but I suppose there're more people who are pro-vax."

Most respondents in this situation, however, simply used the "neutral" option, explaining that they understood it to basically function as a middle point on the attitudinal scale. For instance, when asked why she answered "neutral," one parent said, "Well, I've had both. People who are supportive, but a few of my family are really against it. So, it's both."

Following the third round, the answer categories were expanded to include a "mixed" option to separate these attitudes. Following this change, the "neutral" and "mixed" categories functioned as intended in Rounds 4 and 5.

Answer category language: The first two versions of Question 80, used in Rounds 1 through 4, asked whether or not the discussions they had about childhood vaccines were supportive or not. While a majority of respondents understood this wording to be asking whether or not the

attitudes towards vaccines were supportive or unsupportive during these discussions, a number of respondents instead understood this question to be asking whether or not their family and friends were supportive of them. For instance, when asked to explain why he said "supportive," one respondent in the fourth round said:

> Well, look. A lot of the people on my side are against it [vaccination], because like I said my nephew has Autism. But they support me and [child name], even though it's not what they do.

To reduce this interpretation, the question was edited between Round 4 and 5 to ask whether the conversations were positive or negative. Round 5 testing revealed that respondents universally understood this revised wording to be asking about the intended construct—i.e., about the attitudes discussed during their conversations with family and friends.

Q81: Has a doctor or other healthcare provider ever told you that your child has allergies, including food, drug, or insect allergies?

1. **Yes**
2. **No**

Q82: Has a doctor or other healthcare provider ever told you that your child has blood disorders including sickle cell disease, thalassemia, or hemophilia?

1. **Yes**
2. **No**

Q83: Has a doctor or other healthcare provider ever told you that your child has Down Syndrome?

1. **Yes**
2. **No**

Q84: Has a doctor or other healthcare provider ever told you that your child has epilepsy or a seizure disorder?

1. **Yes**
2. **No**

Q85: Has a doctor or other healthcare provider ever told you that your child has asthma?

1. **Yes**
2. **No**

Q81: Has a doctor or other healthcare provider ever told you that your child has allergies, including food, drug, or insect allergies?

Q86: Has a doctor or other healthcare provider ever told you that your child has diabetes?

1. **Yes**
2. **No**

Q87: Has a doctor or other healthcare provider ever told you that your child has pneumonia?

1. **Yes**
2. **No**

Q88: Has a doctor or other healthcare provider ever told you that your child has the flu?

1. **Yes**
2. **No**

Q89: Has a doctor or other healthcare provider ever told you that your child has Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?

1. **Yes**
2. **No**

Question Design and Background

Questions 81 through 89 are standard chronic condition questions based on similar items in NHIS. They were included in the initial questionnaire (and administered in the first four rounds) to obtain background information on the respondents' children and to prompt probing.

Findings

These questions were not systematically probed, and no findings are available[90].

[90] The Collaborating Center for Questionnaire Design and Evaluation Research, previously the Questionnaire Design Research Laboratory, at NCHS has evaluated these questions previously. For more information, please consult the Q-Bank database at http://wwwn.cdc.gov/QBANK.

Q90: Has a doctor or other healthcare provider ever told you that your child has any health or medical condition that affected your decision to get [him/her] vaccinated?

1. **Yes**
2. **No**

Question Design and Background

Question 90 was included in addition to the standard chronic condition questions (Questions 81–89), and was designed to capture whether or not parents were affected by any other diagnoses not covered by the previous nine questions. This information, similar to what was captured in Questions 81 through 89, was primarily used throughout the evaluation project to provide context to the qualitative findings. However, as opposed to the other chronic condition diagnosis questions, Question 90 was explicitly designed to capture whether or not any diagnoses affected the parents' decisions to vaccinate their children.

Question 90 was designed *de novo*, and is included in the final 5- and 3-minute question sets. It was administered to all respondents across all rounds of testing.

Findings

Respondents universally understood this question to be asking about whether or not their decision to vaccinate, delay, or refuse a vaccination had been impacted by a medical diagnosis. For instance, one respondent who answered "Yes" explained that they delayed the vaccine that her son was supposed to receive at the hospital following his birth, because he had been born a month early and the doctors recommended waiting. Another mother who answered "No" explained that even though her son had been diagnosed at birth with a heart condition, this never impacted their decision to stay on the standard vaccination schedule.

Q91: Has your child ever had a side effect from a vaccination?

1. **Yes**
2. **No**

Q92: Has your child ever had a serious reaction to a vaccination?

1. **Yes**
2. **No**

Question Design and Background

In addition to medical diagnoses, first-hand experiences with vaccine side effects emerged throughout the focus groups as a potential reason for parents to alter their vaccination behavior or lose confidence in the safety of vaccines. Questions 91 and 92 were included in the initial questionnaire in an attempt to capture factual information about the respondents' experiences with side effects and reactions to vaccines (as opposed to their attitudes about side effects, such as captured in Questions 45, 60, and 65).

In Round 1, Questions 91 and 92 were presented in numerical order (91 followed by 92). However, many respondents in the first round either noted that they did not see a difference between the two questions, or requested that they change their answer to Question 91 after they realized that there was a separate item asking about serious reactions. As the goal was to capture minor side effects in Question 91 and more serious ones in Question 92, from the second round onward their order was reversed. Administering Question 92 first provided a framing effect that limited respondents' interpretations of Question 91 to only minor side effects (such as low-grade fevers).

These questions were adapted from similar questions on the NIS-KAP[91] and the National Poll of Parents[92]. They were administered to all respondents in Rounds 1 through 4.

Findings for Question 91

[91] Question 13
[92] Question SEEXPER

Before the question order was reversed, most respondents understood Question 91 to be asking about all severities of side effects. For example, one parent in the first round who answered "Yes" explained that she was thinking about when her daughter "got really sick—fever and vomiting for a week or so after some shots." Another parent who answered "Yes" said that he was thinking about "soreness where [his son] got the shot" that only lasted a day or so.

After the question order was reversed in Round 2, respondents universally understood Question 91 to be asking about less-than-serious side effects. These ranged from low-grade fevers, to soreness and fussiness, to stomach issues, to lethargy. Most parents who answered "Yes" explained that the symptoms cleared up in a few days. For instance, one father in the third round who answered "Yes" noted that he was thinking about the fact that after one set of shots his son "vomited and had nausea. It was one short episode, and that was the only time."

Findings for Question 92

Regardless of the question order, respondents universally understood Question 92 to be asking about serious side effects and reactions to vaccination. For instance, one parent who answered "Yes" explained that she was thinking about the fact that her daughter got really sick after her 1-year shots: "She was sick for several days and vomited for several days. Not much you can do about it—we sort of expected it, because we had heard that the 1-year shots are sort of a bear." When asked why she considered it serious, this respondent said, "Any time you have a little person who is vomiting, it's a serious thing." She went on to note that her daughter got dehydrated and they had to go see a doctor.

A number of parents applied this criterion—equating requiring a hospital or doctor visit to whether or not a reaction was "serious." For example, one mother in the third round who answered "No" said that while her daughter had had soreness after vaccinations, she considered "serious" reactions to be "Anything that requires a visit to urgent care or the emergency room."

Q101: How confident are you that all of the vaccines your child's doctor recommended so far are necessary?

1. **Very Confident**
2. **Somewhat Confident**
3. **Not at all Confident**

Question Design and Background

Following the analysis of the first three rounds of cognitive interviews, it became clear that a simple measure of a respondent's trust in their pediatrician's advice vis-à-vis childhood vaccines may prove useful when attempting to explain why a parent was vaccine hesitant or not. Question 101 was written *de novo* in an effort to capture this information. It was administered to all respondents in Rounds 4 and 5, and is included in the final 5- and 3-minute question sets.

Findings

Respondents universally understood this question to be asking about their confidence in their child's doctor's recommendations about getting vaccinated. Two patterns of judgment emerged as respondents arrived at their answers: they either focused on their doctor's credentials or on their belief in the necessity of the vaccines, as shown below in Figure 23:

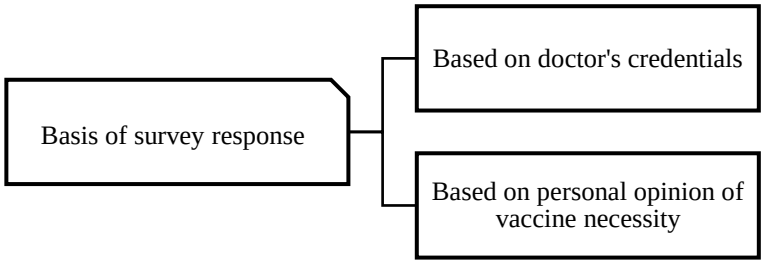


Figure 23. Patterns of Judgment for Question 101

Respondents who applied the first pattern of judgment explained that they were confident in their doctor because of his or her credentials or experience. For example, one mother in Round 5 explained her "Very confident" response by stating:

> I guess she [the pediatrician] knows because she's my doctor. As an educated person, I guess that's not a fair response, but it's not something I've challenged. I trust the fact that I'm relying on an expert with my daughter's care. Somebody who helps me with my decisions, and these are the things she tells me. So, I haven't really questioned that. Maybe it's ignorance on my behalf, or maybe it's

> recognizing that this is what she went to school for and it's her expertise. Just like I have my expertise. It takes an army to raise a child, and so I recognize that's what she provides.

Even when parents had some personal doubts about vaccines, those using this pattern believed that the doctor's opinion outweighed their hesitations. A good example of this was a father from Round 4 who was concerned specifically about the HPV vaccine for his daughter. He answered "Very Confident" to Question 101, and explained that while he harbors some hesitance to the HPV vaccine, he trusts that his daughter's school and doctors have a good reason for labeling some vaccines required and others not: "I would hope the doctor and the school know about the vaccines—and I just trust that they know what they're about…HPV isn't required right now, so she probably isn't going to get it." Upon further probing, he went on to explain that if the school or doctor required her to get the HPV shot, he would allow it, because "…they would have a good reason for saying she had to get it."

On the other hand, some parents based their responses on whether or not they believed that the vaccines were necessary, sometimes regardless of what their child's doctors said. One mother in Round 4 answered "Very confident," and when asked why she believed this said, "Well I don't know all the vaccines. If I knew more about what they got. But I think vaccines are pretty necessary." For the respondents using this pattern, this underlying belief in (or against) the necessity of vaccines outweighed the doctor's recommendations. For instance, one mother who answered this question "Not at all confident" explained that so far, when she has weighed the positives of vaccines against what she perceives as their risks, she has always "come down on the side of not getting [her daughter] vaccinated." She went on, saying, "And one side is telling me, 'a doctor would know since it's what they went to school for.' But on the other hand, you know it's...it's shaky."

Respondents' confidence in the fact that recommended vaccines are necessary appeared to line up well with their overall attitudes towards childhood vaccines. Table 9 compares respondents' answers to Question 35 (the overall vaccine hesitance question, in the columns) to Question 101 (in the rows).

Table 9. Round 4 and 5 Respondents' Answers to Question 35, by their Answers to Question 101

	Not at all hesitant	Not that hesitant	Somewhat hesitant	Very hesitant
Very Confident	8	1	1	0
Somewhat Confident	0	0	5	2
Not at all Confident	0	0	2	2

An apparent correlation between overall vaccine hesitance and a lack of confidence in the necessity of recommended vaccines is clear among the 21 respondents in the final two rounds of cognitive testing—respondents who were not confident were more likely to be vaccine hesitant, whereas respondents who were confident were less hesitant.

Q102: Do you personally know anyone who has had a serious, long-term side effect from a vaccine?

1. **Yes**
2. **No**

Question Design and Background

Throughout the cognitive interviewing process, personal knowledge of someone who had had a negative experience with vaccines emerged as an important factor in respondents' explanations of their hesitance toward vaccines. The initial questionnaire only included questions about personal *experience* (i.e., Questions 91 and 92), but an analysis of the data from the first four rounds showed that these questions did not fully capture the factor that appeared to be driving respondents' attitudes. As a result, Question 102 was designed to explicitly capture this knowledge component.

The question's design was based on similar questions in the PACV[93] and the National Poll of Parents[94] questionnaires. It was administered to all respondents in Rounds 4 and 5, and is included on the final 1-, 3-, and 5-minute question sets.

[93] Question 14
[94] Question PRKNOINJ

Findings

Respondents all understood this question to be asking about someone they personally knew, in real life (as opposed to knowing somebody just online). Respondents who answered "Yes" were mostly thinking about family members and close friends. For instance, one respondent who answered "Yes" said that she was thinking about her husband's son (from a previous relationship) who had terminal cancer that the family had linked to vaccines (note that she had explained that it was the family's suspicion that the cancer was related to vaccines, but that this was never confirmed in any way by a doctor or health provider).

A few respondents who answered "No" explained that they knew of somebody who supposedly had a serious reaction to vaccines, but they did not think about them as somebody they "personally" knew and therefore could not answer "Yes." For instance, one mother who answered "No" paused for a few moments before providing an answer, and when asked why explained:

> So, I know of someone through a friend of a friend. She posts a lot, but it's not her child [who had the reaction] …She went strongly anti-vax when a friend of hers lost a baby, and they placed the blame fully on the vaccines...and it really changed her opinion and she's really opinionated now about vaccines.

However, this mother noted that since the person who actually had the reaction (a child of a friend of a primarily online friend of the respondent's) was not a personal friend, she had to answer "No."

Overall, respondents' answers to Question 102 appeared to help explain their attitudes of vaccine hesitance or confidence. All eight respondents who answered this question "Yes" (indicating that they did indeed have a personal connection to somebody who had a serious reaction to vaccines) indicated that they were either "Somewhat" or "Very hesitant" towards childhood vaccines in Question 35.

Q103: Is your child's doctor or health provider your most trusted source of information about childhood vaccines?

1. **Yes**
2. **No**

Question Design and Background

While the importance of determining the most (and least) trusted sources of information on childhood vaccines was clear throughout this project, analysis of the first three rounds of cognitive interviewing data indicated that a simple, to-the-point question may provide the best information. In the early rounds, question sets such as Questions 71–72, 73–74, and 75–79 attempted to capture this information, but respondents consistently found these approaches confusing or burdensome. Given this, a new question was designed for Round 4 that specifically asked respondents whether or not their child's pediatrician was their primary source of information.

The design of this question was based on similar questions in the PACV[95] and National Poll of Parents[96] questionnaires, and was administered to all respondents in Rounds 4 and 5. It is included on the final 1-, 3-, and 5-minute question sets.

Findings

Respondents understood this question to be simply asking whether or not their child's doctor was their primary source of information. Respondents who answered "Yes" indicated that they were, and cited a number of reasons for this—mostly because they felt like the doctor had the experience and knowledge needed. For instance, one father who answered "Yes" indicated that they relied on the doctor for this information because that was their job: "Do I trust the doctor? I have to! I don't have time to be fully educated. So, at some point, I just have to trust them." Likewise, a mother who answered "Yes" explained:

> [Her son's] current doctor is really, really good. We actually went to him when another doctor gave us information that was questionable. So, his current doctor, I would say, we follow whatever he says. Whatever he recommends.

[95] Question 18
[96] Question KABS8-10

On the other hand, respondents who answered “No” all explained that they either did not trust doctors, or relied on other sources of information just as much as the doctors. For example, one respondent who answered “No” explained that she just did not think that doctors always had her daughter’s best interests in mind: “It's a business and he [the doctor] has to make money…[Doctors] don't provide 100% of the facts. They have to sell medicine—which is a product—just like any other business.” Others said that they relied equally or more heavily on other sources—the most common of which was “themselves,” by which they meant researching online. For instance, when asked why he answered “No,” one father said, “No. I do my research, like going to WebMD. I’ll take that research to [his daughter’s] doctor, but she respects my decision ‘cause I did the research.”

Just as with Question 102, all the respondents who answered this question “No” (7 out of the 21 who received it in the last two rounds) noted previously in Question 35 that they were either “Somewhat” or “Very hesitant” about childhood vaccines. This indicates that Question 103 captures information that can reliably explain a parent’s childhood vaccine hesitance.

Works Cited

Anderson, Ronald. 1995. Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behavior* 36(1): 1-10.

Becker, M.H. 1974. "The health belief model and personal health behavior." *Health Education Monograph* 2:324-508.

Brown, Katrina F., Kroll, Simon J., Hudson, Michael J., Ramsey, Mary, Green, John, Long, Susannah J., Vincent, Charles A., Fraser, Graham, and Nick Sevdalis. 2010. "Factors underlying parental decisions about combination childhood vaccinations including MMR: A systematic review." *Vaccine* 28(26): 4235-4248.

Miller, Kristen, Willson, Stephanie, Chepp, Valerie, and José Luis Padilla. 2014. *Cognitive Interviewing Methodology*. Hoboken, NJ: Wiley and Sons.

Opel, Douglas J., Mangione-Smith, Rita, Taylor, James A., Korfiatis, Carolyn, Wiese, Cheryl, Catz, Sheryl, and Diane P. Martin. 2011. "Development of a survey to identify vaccine-hesitant parents." *Human Vaccines* 7(4): 419-425.

Prislin, Radmila, Dyer, James A., Blakely, Craig H., and Charles D. Johnson. 1998. "Immunization status and sociodemographic characteristics: The mediating role of beliefs, attitudes, and perceived control." *American Journal of Public Health* 88(12): 1821-1826.

Salmon, Daniel A., Sotir, Mark J., Pan, William K., Berg, Jeffrey L., Omer, Saad B., Stokley, Shannon, Hopfensperger, Daniel J., Davis, Jeffry P., and Neal A Halsey. 2009. "Parental vaccine refusal in Wisconsin: A case-control study." *Wisconsin Medical Journal* 108(1): 17-23.

Sears, Robert W. 2007. *The Vaccine Book: Making the Right Decision for your Child*. New York, NY: Little Brown and Company.

Smith, J. Jerome. 1993. "Using ANTHOPAC 3.5 and a Spreadsheet to Compute a Free-List Salience Index." *Cultural Anthropology Methods Newsletter* 5(3): 1-3.

Taylor, Luke E., Swerdfeger, Amy L, and Guy D. Eslick. 2014. "Vaccines are not associated with autism: An evidence-based meta-analysis of case-control and cohort studies." *Vaccine* 32(29): 3623-3629.

Tourangeau, Roger, Rips, Lance J., and Kenneth Rasinski. 2000. *The Psychology of Survey Response*. New York, NY: Cambridge University Press.

Appendix A: Conceptual Framework for Developing the Initial Questionnaire

To select question topics for a vaccination hesitance survey, researchers at the Coordinating Center for Questionnaire Design and Evaluation Research developed a conceptual framework. Specifically, a behavioral model for vaccine hesitancy was developed, based in part on two well-described existing conceptual frameworks: Behavioral Model of Health Service Use (Andersen, 1995) and the Health Belief Model (Becker, 1974). These conceptual approaches provide guidance to understanding the relationships associated with vaccination hesitance and other factors connected to childhood vaccination.

Historically, the Behavioral Model of Health Services Use is a framework for understanding an individual's utilization of health care services (Andersen, 1995).

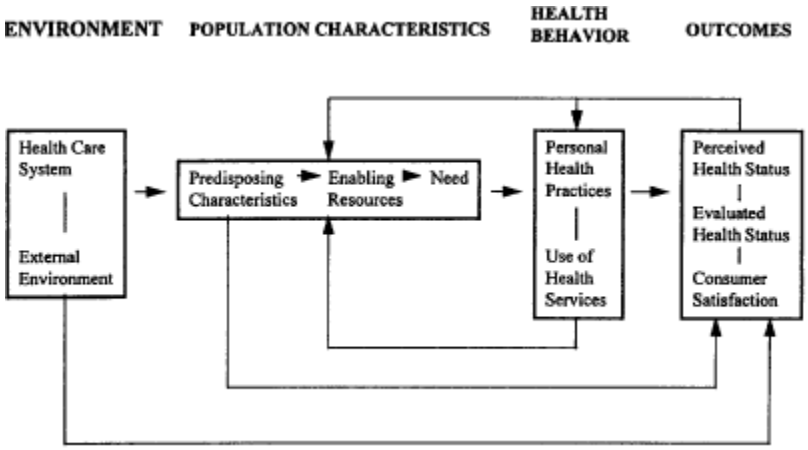


Figure 24. Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? From Anderson, 1995

To understand how health services are used, the behavioral model focuses on three main types of explanatory factors: predisposing characteristics, enabling resources, and perceived need. Over time, this model evolved to include additional health behavioral and health outcome elements to account for the relationships between both the explanatory factors in the population and health outcomes and service use. It has been widely used to describe how specific populations use health care services and examines the determinants of utilization. Considering child vaccination, there are several factors that this behavioral model emphasizes that can explain vaccine hesitance: the health care system and external environment, characteristics of the population, which includes health beliefs and attitudes about vaccination, enabling resources to cover the

costs associated with vaccination, and the perceived need for specific health services. Lastly, how do those population characteristics relate to health behavior and health outcomes?
There are certain components within the model that have varying degrees of mutability—that account for how much a component can vary over time. Components with low mutability remain relatively stable and are not altered to change utilization (or in this case vaccination), which also includes predisposing characteristics like demographic and social structure components like sex, age, ethnicity, and race. Health beliefs, on the other hand, have a medium degree of mutability as they can be altered and sometimes affect health behavioral change (getting vaccinated). Enabling factors like insurance can have high mutability and can have dramatic implications for one's health service use (and vaccination).

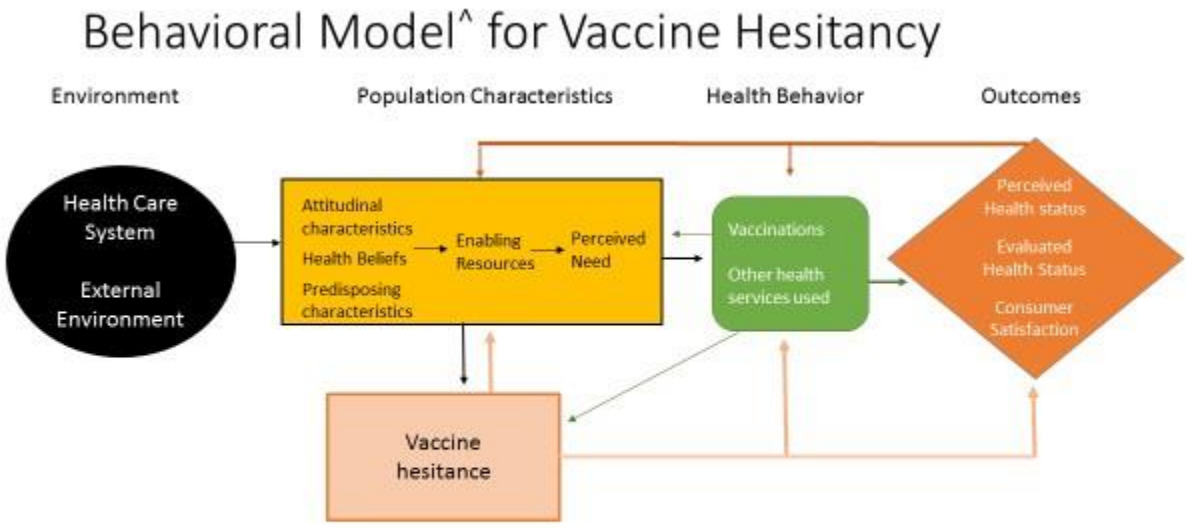
The Health Belief Model (HBM) represents a widely-used approach to understanding why individuals did or did not engage in a wide variety of health-related actions and for explaining and predicting the acceptance of health and medical care recommendations, such as getting a child vaccinated. HBM consists of using individual perceptions, modifying factors, and likelihood of action across the dimensions of perceived susceptibility, perceived severity, perceived benefits, and perceived barriers to predict health behavior.

For understanding vaccine hesitance and the childhood vaccination behavior among parents, this modified conceptual framework including elements of HBM within the Behavioral Model of Health Service Use may apply to vaccination. Here, a modified Behavioral Model for Vaccine Hesitancy provides a way to consider how the environment, the characteristics of a population, specific health behaviors (e.g., vaccination), and health outcomes (e.g., perceived health, patient satisfaction) relate to vaccine hesitance.

The Behavioral Model for Vaccine Hesitancy

Since health beliefs can be viewed in terms of perceived susceptibility, severity, benefits, and barriers, and most types of vaccination services interface with the health care system and external environment, the enabling factors associated with accessing medical care, such as insurance, become important. It is in this spirit that questions considered for inclusion in these 1-,

3-, and 5-minute questionnaires were selected in conjunction with a modified behavioral model around the environment.



^Model is based on Behavioral Model of Health Service Use (Andersen, 1995) and the Health Belief Model (Becker, 1974).
Andersen, R.M. 1995. "Revisiting the Behavioral Model and Access to Medical Care: Does It Matter?" *Journal of Health and Social Behavior* 36: 1-10.
Becker, M.H. 1974. "The health belief model and personal health behavior." *Health Education Monograph* 2:324-508.

Figure 25: Behavioral Model for Vaccine Hesitancy

A Behavioral Model for Vaccine Hesitancy using the HBM and behavioral model was used to select questions to understand an individual's utilization of vaccination services.
In this model, population characteristics, health behaviors, and health outcomes explain vaccine hesitance. The environment provides context to whether population characteristics and hesitance ultimately influence health behaviors. Next, each main element of the selection model is described with questions supporting each element that were evaluated in this study.

Environment:
The environment refers to the health care system and external environment. Questions on the environment may include the health care system or context about where the child lives.

- Place child goes when sick, needs preventive care, or needs advice about their health. (Q: 11–14, 16)

Population Characteristics:
Population characteristics may explain a range of factors relating to vaccine hesitance, which includes predisposing characteristics, enabling resources, and perceived need.

Predisposing characteristics include demographic characteristics, social structure, and health beliefs. Demographics like age, race and ethnicity, and sex questions were not included. Social structure was included for understanding the degree of support for or against vaccination in the parent's immediate social network. For health beliefs, questions that were selected included items around parent's perceived susceptibility, perceived severity, perceived benefits, and perceived barriers to vaccination, which may have a direct relationship with vaccine hesitance. Here, health beliefs may either reduce or increase one's vaccine hesitance. Health beliefs can relate to the perceived benefits of vaccines—that is, trust in information about them, and a level of confidence that vaccines are effective, safe, and beneficial. Other health beliefs may relate to parental concerns or perceived barriers to vaccination, such as a lack of trust in information, a lack of confidence that vaccines are effective, safe, or concerns about children getting vaccinations. Health beliefs about perceived disease severity and perceived susceptibility may also influence vaccine hesitance.

- Social structure: Support or oppose vaccination (Q: 80, 80a)
- Social structure: Health care provider information (Q: 17, 18)
- Health beliefs: Physician experience and doctor (Q: 23, 26, 27, 29)
- Health beliefs: Vaccine confidence (Q: 33, 33a, 36–47a, 49–70, 101)
- Health beliefs and trusted sources of information (Q: 32,71–79, 103)

Enabling resources to vaccination may relate to having insurance or being able to pay out-of-pocket costs of vaccination, or having community support for vaccination.

- Child covered by health insurance (Q: 8)
- Problems paying for child's medical bills (Q: 9)
- Delaying or not receiving needed care (Q: 15)

Parents may have various perceived needs for getting their children vaccinated. Parents may perceive their child has a medical need that relates to whether or not their child gets vaccinated. For example, a chronic condition may affect whether a parent is hesitant because a doctor may explain vaccination is helpful or harmful for the child's health.

- Child plans on receiving vaccine (Q: 3, 5)
- Follow the standard or recommended vaccine schedule (Q: 5a, 5b)
- Seeking MDs to either follow or not follow the standard schedule (Q: 28, 28a)
- Delayed, refused a vaccine (Q: 48, 48a)
- Know someone with a serious reaction from vaccination (Q: 102)
- Child had a serious reaction/side effect (Q: 91, 92)
- Child needs or uses medicine (Q: 7)

- Chronic conditions that may influence vaccination (Q: 81–90)

Health Behavior
Health behavior in this model describes whether parents got their child vaccinated.

- Child received vaccinations—all recommended childhood vaccinations, flu, or HPV (Q: 1, 2, 4)

Health Outcomes
Health outcomes relate to perceived health status, evaluated health status, or measure of consumer satisfaction with their child receiving their vaccinations.

- Perceived health status (Q: 6)
- Satisfaction in the delivery of health care (Q: 10, 19–22, 24, 25)

Appendix B: Brief Overview of Focus Group Methodology and Findings

Staff from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at the National Center for Health Statistics (NCHS) conducted a series of five focus groups in September and October of 2016 as a first step in the design of multiple short vaccine hesitance and confidence question sets for the National Center for Immunization and Respiratory Diseases (NCIRD). This Appendix provides a brief overview of the protocols used in these focus groups and some of the major themes that emerged from the group discussions.

Focus Group Methodology

Five focus groups were conducted in NCHS' Questionnaire Design Research Laboratory across three weeks in September and October 2016. Groups were divided by race (African American and not African American) and education (less than college degree and college degree or more), as shown in Table 10:

Table 10: Demographic Breakdown of Focus Groups

	African American	Other than African American	Less than College Degree	College Degree or More
Focus Group 1	●			●
Focus Group 2	●		●	
Focus Group 3		●		●
Focus Group 4		●	●	
Focus Group 5	●			●

CCQDER recruited 31 participants across the five groups. The participants were all parents with at least one child under 13 years. The respondents' characteristics are shown below in Tables 11 and 12:

Table 11: Focus Group Participants' Race, by Gender

	Black or African American	White	Asian	Hispanic	Native American or Alaskan Native
Male	7	2	0	1	1
Female	12	5	2	1	0

Table 12. Focus Group Participants' Education by Gender

	Less than High School	High School	Associate's Degree	Bachelor's Degree	Graduate Degree
Male	0	1	1	6	3
Female	1	3	1	5	6

The group discussions were all semi-structured around a common protocol, including a discussion of both vaccine hesitancy and confidence, as well as four freelisting activities. The moderators did their best to not impose themselves, and therefore, each discussion varied. Participants spoke about their trust in the healthcare system, the sources of information they trusted and relied on (or shied away from) when making health decisions for their children, and their attitudes about childhood vaccines. The discussions explored both the benefits and perceived risks of vaccinations, how parents differentiated between different types of vaccines, and how they ultimately made vaccination decisions for their children.

Freelisting Results

In addition to the typical discussions of a focus group, participants were also asked to complete four individual freelisting activities. At four separate points during the focus groups, respondents were asked to respond to a prompt by listing as many items as they could on a sheet of paper. These prompts were designed to elicit a more complete understanding of the domains surrounding trust in healthcare information sources and the perceived risks and benefits of parents vaccinating their children. All of the lists were then compiled, edited, and analyzed following Weller and Romney, 1998. Freelisting elicits individual items in a cognitive domain (such as the benefits of vaccination) by asking respondents to write down all of the things in that domain that they can. The theory behind freelisting assumes that respondents will list the items that are most salient and meaningful first; by analyzing item placement across all of the participants' lists, a determination can be made as to whether or not particular items are culturally salient.

The first prompt asked respondents to list the sources they trusted and felt they could rely on when making healthcare decisions for their children. The figure below shows the composite salience (Smith's S score) for all the sources that participants listed.

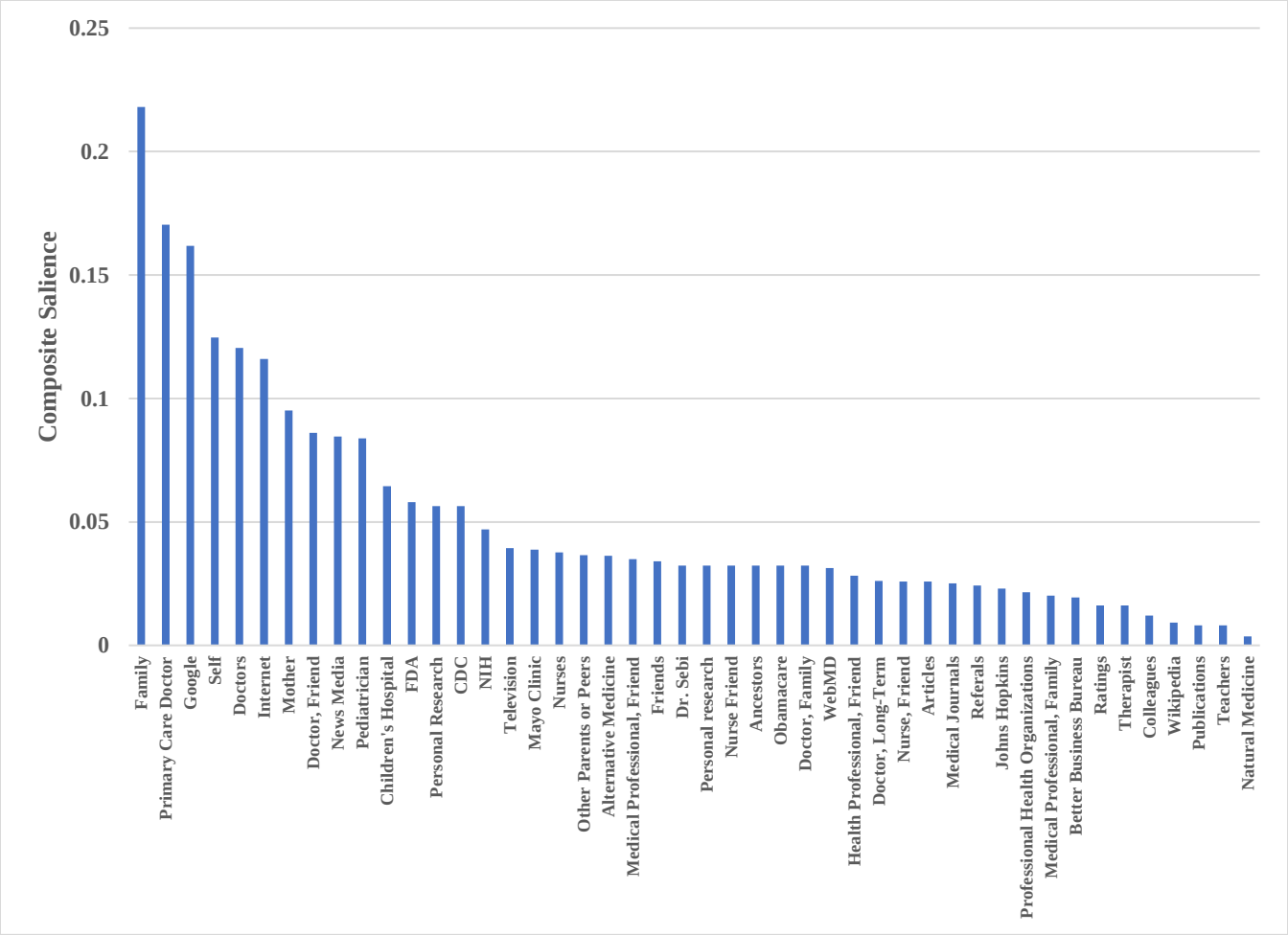


Figure 26: Trusted Sources of Healthcare Information

General family members were the most salient (and most frequently cited) trusted sources of healthcare information. Various types of doctors, friends, and personally conducted research using internet searches also appear to be important sources of information. Government agencies, such as CDC, FDA, and NIH, while not among the most salient sources, do appear in the top one-half of the composite list.

The second prompt asked respondents to consider the opposite of the first, and asked them to list sources they either could *not* trust or could not fully trust when making healthcare decisions for their children. Figure 27 shows the composite list from this prompt by the various sources' salience scores:

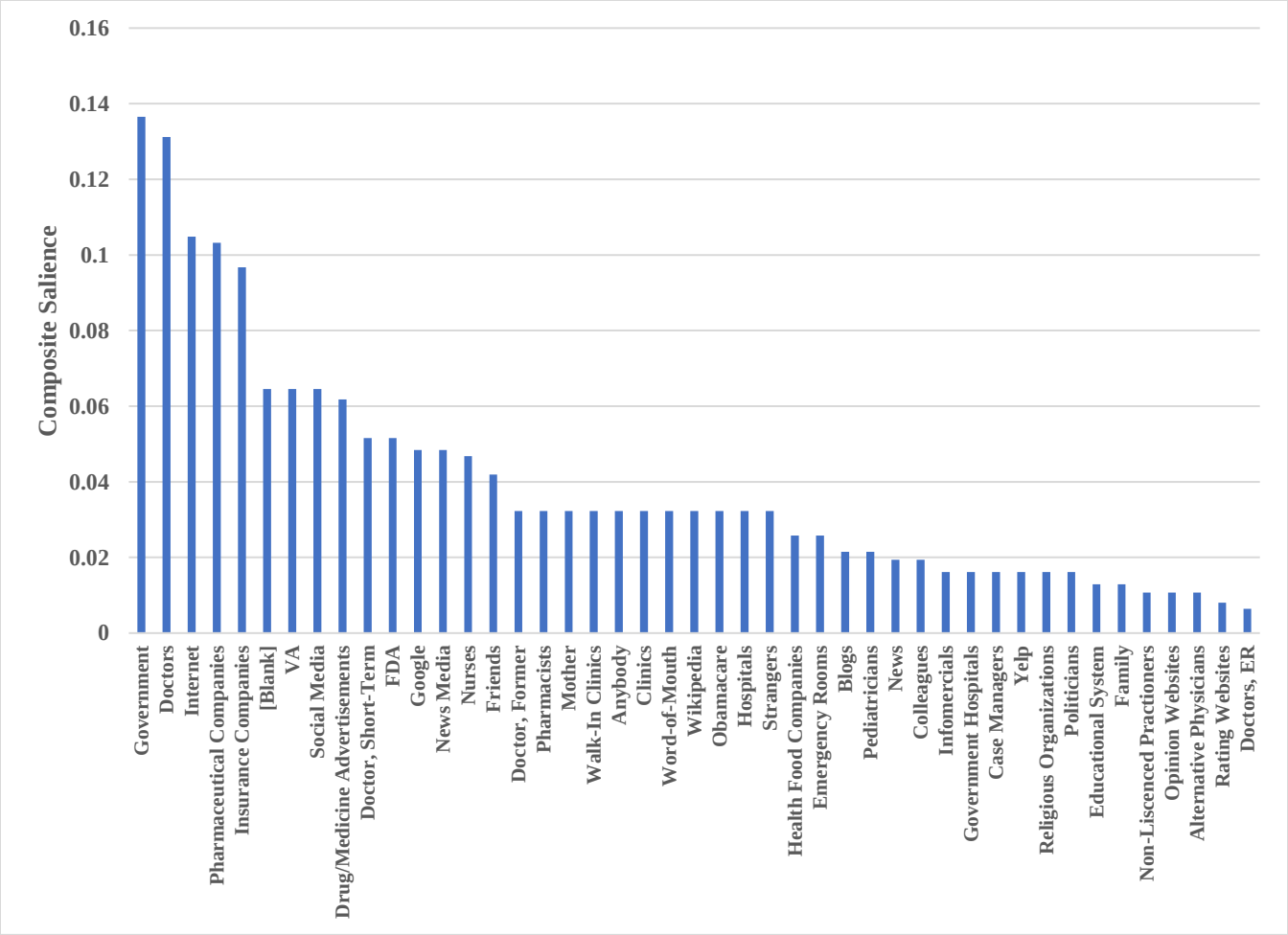


Figure 27: Distrusted Sources of Healthcare Information

There is an overlap between highly salient trusted sources and highly salient distrusted sources—with a number of respondents mentioning that they both trusted and did not trust the government, doctors, or the internet when making healthcare decisions for their children. When asked about this apparent contradiction in the discussion, a nuanced set of rules determining whether or not parents trusted doctors' advice emerged. On one end, parents argued that doctors represented the visible part of the healthcare system, and could not be trusted because healthcare was "just a business" and did not have their children's best interests at heart. However, many parents noted that they trusted *their* primary care physician (PCP) or pediatrician, even if they distrusted doctors in general. For instance, one participant in the second group noted that she trusted her own PCP because she had gone to him since she was a child.

The third prompt asked respondents to list the benefits of ensuring that their children had their childhood vaccines. As can be seen below in Figure 28, the most salient reasons parents had for getting their children vaccinated dealt directly with their health:

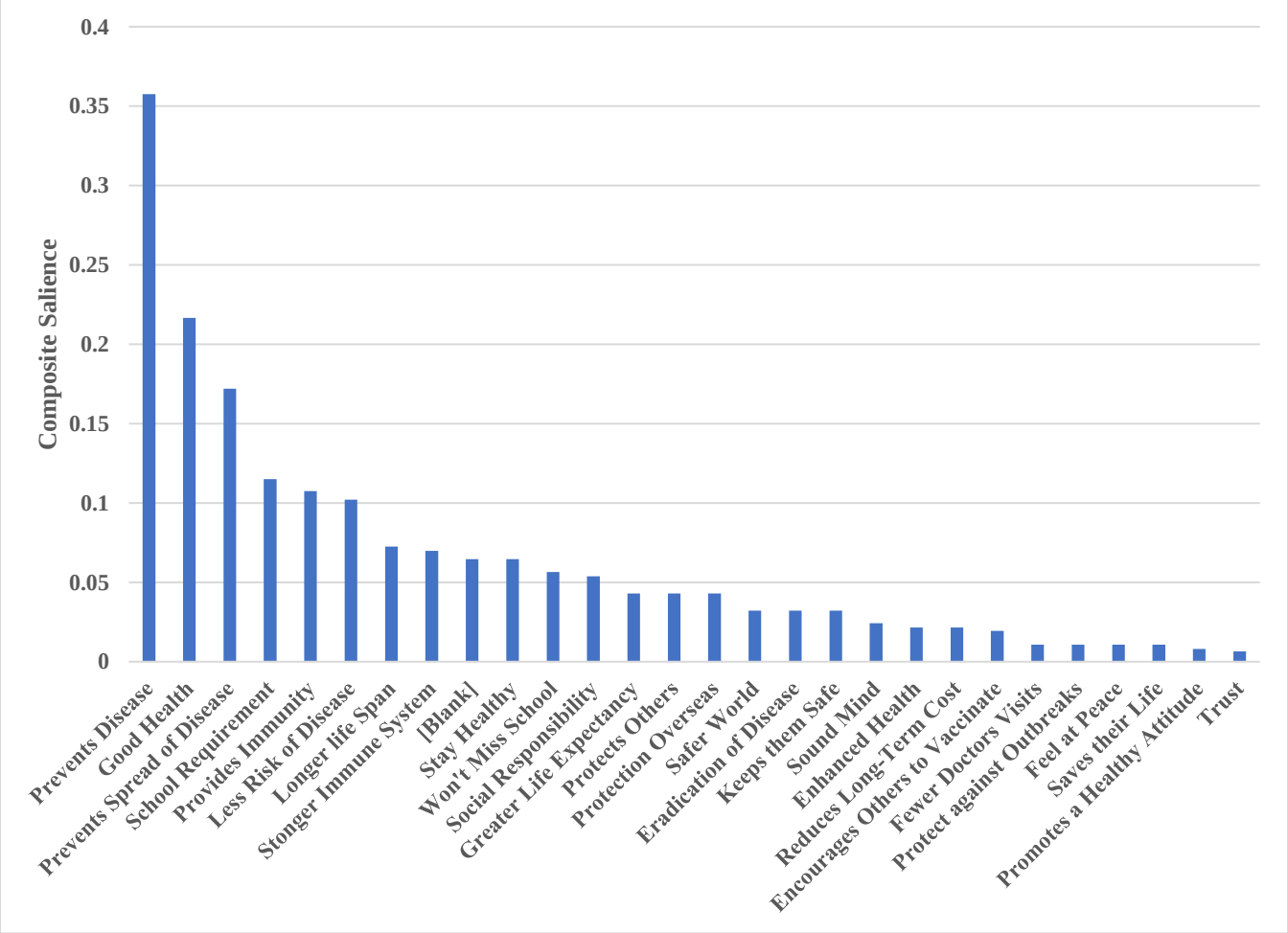


Figure 28: Benefits Associated with Childhood Vaccinations

In fact, most of the reasons that parents gave—from prevention of disease to providing immunity—directly related to their children's health. The most obvious and salient exceptions to this were two reasons that related to their children's ability to get into and attend a school—the fact that most school districts require certain vaccinations before a child attends school, and the perception that vaccinations help prevent a student from needing to take a sick day.

The final prompt asked respondents to list the risks of childhood vaccinations and the reasons why they would be hesitant towards getting their children vaccinated. The most frequent and salient reason contributing to vaccination hesitancy was the risk of harmful or unknown side effects. Participants commonly cited symptoms such as fevers and mild illnesses, but a few

mentioned serious side effects such as seizures and even death. Related to this, a number of respondents indicated that by getting a vaccine, their child could actually get sick with the illness that the vaccine was designed to prevent. As can be seen in Figure 29, these two reasons were by and large the most salient across the compiled lists, with other risks having at most 1/3 of the salience of these two:

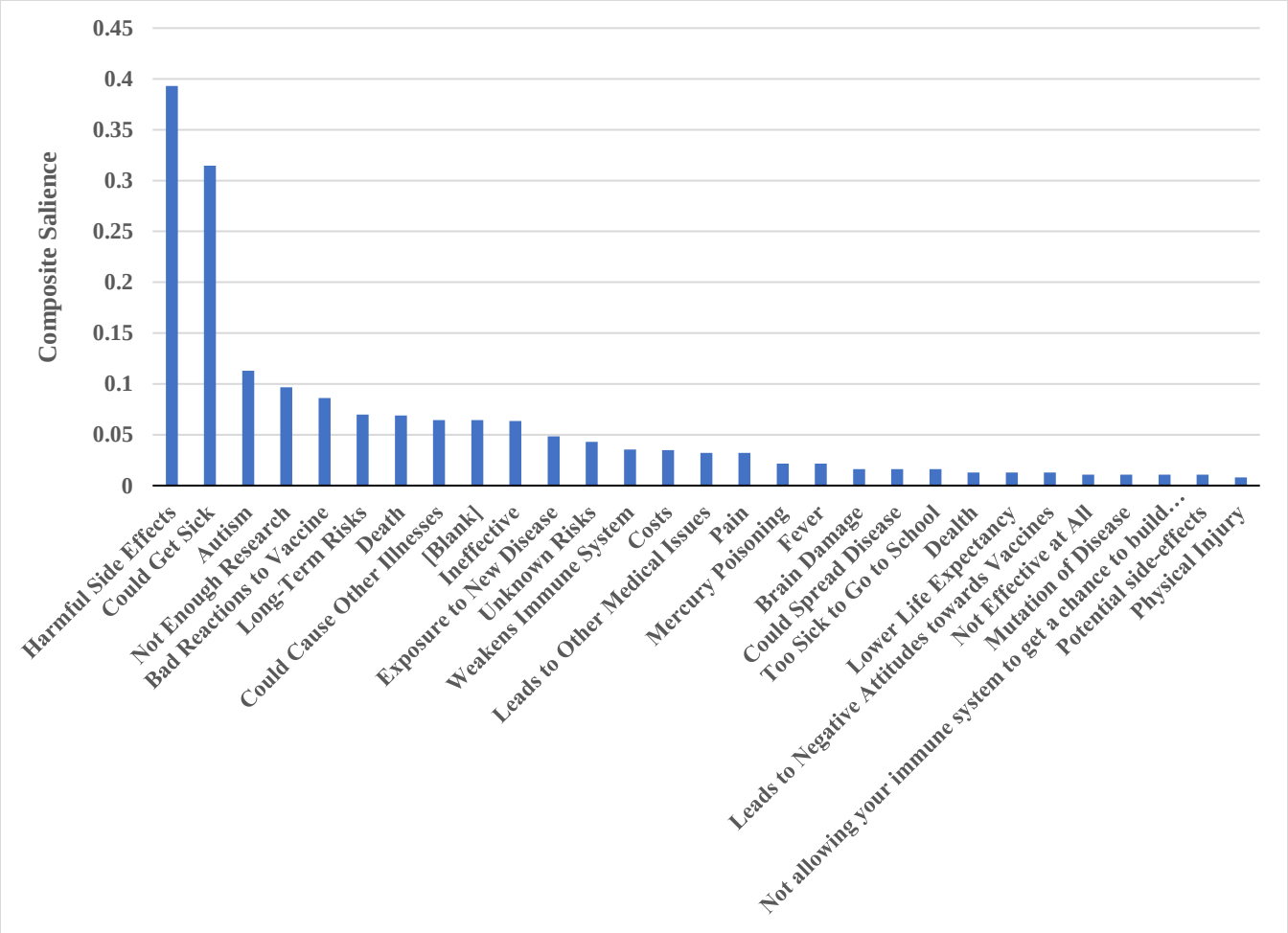


Figure 29: Risks Associated with Childhood Vaccinations

Discussion Themes

As noted above, the focus group discussions were driven by a protocol that insured that participants talked about their overall impressions of the healthcare system, whom they could trust when making healthcare decisions for themselves and their children, their decision-making process in regards to vaccines, and their general perceptions of vaccines' risks and benefits.

From these conversations, a number of common themes emerged that will be used to inform the design of an initial vaccine hesitance and confidence questionnaire.

Overall Trust in the Healthcare System

Parents indicated that they do not trust the system as whole, but rather trust individual components within the system—for instance nurses and some doctors. Unsurprisingly, participants most frequently noted that they did not trust health insurance or pharmaceutical companies due to the perceived conflict of interest. When explaining their distrust of the healthcare system, most parents noted that "it was a business," that the health care system's primary concern was to make money, not ensure good health. Doctors and nurses fared better in the esteem of the participants, but not evenly: they tended to trust nurses more than doctors as a group. The trust differences between doctors and nurses relate to the amount of time they spend with patients and communication styles. Some parents noted nurses talk to them more than doctors do, and that doctors don't have "a personal touch." Others noted that physicians don't spend as much time with patients or take the time to explain things.

Trusted and Distrusted Sources of Healthcare and Vaccination Information

Parents' decisions to trust or distrust doctors and other health care professionals were largely based on experience. If the doctor was a long-time or family doctor (or a health professional who was also a relative or family friend), parents noted that they were more likely to listen to her or his medical advice for their child's care or treatment. Conversely, some attributed distrust to those who had bad experiences with nurses and doctors alike. For newer doctors with whom they had little rapport or experience, many parents noted that they did not completely believe or trust their advice. Again, some parents believed that recommendations from these doctors were motivated by profits and factors outside the patient's best interests.

Beyond healthcare professionals, parent's perceptions of trust in recommendations put out by the government were mixed. Some viewed the government agencies like CDC and FDA as very helpful and trustworthy when considering medical decision-making. They specifically thought about using these agencies' websites as resources when making decisions about vaccinations specifically, and healthcare in general. Others, however, indicated a deep-rooted distrust of the

government. A number of these participants cited the Tuskegee Syphilis Experiment, while others mentioned conflicts of interest with health care access. This distrust extended across federal, state and local government.

As seen in Figures 26 and 27, participants both trusted and distrusted commercial internet sources of information, such as Google. While most respondents noted that they could not always be sure of the veracity of internet content, many indicated that they used general web searches to begin their self-education on healthcare topics. For instance, one respondent in the fourth group noted that she used a Google search to begin researching the HPV vaccine, but only really paid attention to "sites I trust." When asked to give examples of these sites, she mentioned the CDC site and WebMD. Another parent noted that she would search about medicines and vaccines online and "read and read and read" until she felt like he had a good handle on both the potential risks and benefits.

Vaccination Decision-making

By and large, parents separated vaccines into two groups: old (and trusted) vaccines and new (and untrusted or potentially worrisome) vaccines. For example, most of the vaccines on the childhood schedules (such as DTaP and MMR) were vaccines that parents noted that they had as children too.

Two factors appeared to contribute to the trust in these "older" and established vaccines (and conversely took away from the parents' trust in newer vaccines). The first factor was simply personal experience—if respondents had the vaccine themselves and suffered no adverse consequences, it followed that the vaccine was safe for their children. Secondly, parents indicated that these older vaccines had been thoroughly "tested," and therefore posed little risk to their children.

The concept of "testing" was particularly noticeable when the participants discussed newer vaccines (such as HPV, chicken pox, and a potential Zika vaccine). A number of parents indicated that they did not want their children to take recently developed vaccines because they did not want their kids to function as "lab rats" or "test cases." One respondent in the fifth group

explained, “They [newer vaccines] aren’t tested enough—I’m fine with [my child] being vaccinated, but I need to know it’s safe first, and I just don’t think they’ve been well tested.” Parents such as this gentleman either did not believe in the integrity of government testing requirements (because they believed that government agencies could be bought off by pharmaceutical companies) or simply did not know that agencies such as the FDA require extensive testing in the first place. Another parent indicated that the number and volume of vaccines given to his child at one time were a concern, and he was not sure about the safety, especially as it pertained to his child who was later on diagnosed with autism.

Beyond the issues of the “age” of the vaccines in question, parents turned to their trusted sources from above to help them make decisions about whether or not to get their child vaccinated. In general, parents did not indicate that they had much difficulty making decisions about the early childhood vaccines (i.e., those on the birth to 15-month schedule). Rather, most parents noted that they just followed their pediatricians’ recommendations. More complex decisions became apparent when parents spoke about vaccines in the 18 months to 18 years schedule—particularly ones such as HPV, Hepatitis A, influenza, and chickenpox. While most parents noted that they did extensive research into these, even if their doctors recommended them, their decisions often came down to whether or not these vaccinations were required for acceptance into schools or other activities in which their children might participate.

Confidence in Vaccine Effectiveness and Contributors to Hesitancy

Discussions of both vaccine effectiveness and hesitancy centered on parents’ perceptions of the side effects from the inoculation. If a vaccine was not perceived as having too many negative side effects, parents largely considered it effective and did not indicate hesitancy. On the other hand, vaccines that were known to have side effects were considered the least effective and parents noted that they were less likely to follow the schedule and ensure that their children were inoculated.

The best example of this is the influenza vaccine. Nearly all of the participants noted that either they personally or someone close to them had fallen ill after getting the flu shot. Combined with the fact that many of them still got the flu after taking the annual influenza vaccine, a large

number of parents in the focus groups indicated that they did not get the flu shot for their children.

A few other side effects were mentioned—including the idea that vaccines could lead to autism or lead poisoning. One of the most commonly cited reasons for why a parent might not get a vaccine for their child was the pain their kid felt from the shot itself. For instance, one mother simply noted, “I don’t want my child to be hurt—I don’t like it.” This came up most frequently when parents were discussing the “optional” vaccines (i.e., ones that are not required for school acceptance), such as HPV, chicken pox, and the flu shot.

Appendix C: Round 1 Questionnaire

Outcome Section

1. Has your child received all, some, or none of the recommended vaccines to date?
    1. All of them
    2. Some of them
    3. None of them
    7. Don't Know
    9. Refused

2. During the past 12 months, has your child received a flu shot? A flu shot is usually given in the Fall and protects against influenza for the flu season.
    1. Yes
    2. No
    7. Don't Know
    9. Refused

3. How often does your child receive the annual influenza, or flu, shot?
    1. Every Year
    2. Some Years, but not Every Year
    3. Never
    7. Don't Know
    9. Refused

4. Has your child received a HPV shot?
    1. Yes [SKIP to 6]
    2. No [GO TO 5]
    7. Don't Know [GO TO 5]
    9. Refused [GO TO 5]

5. [IF Q4=2,7, or 9] Are you planning for your child to receive the HPV shot in the future?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

Perceived Needs and Access

In general, how would you describe your child's health?
    1. Excellent
    2. Very Good
    3. Good
    4. Fair
    5. Poor
    7. Don't Know
    9. Refused

7. Does your child currently need or use medicine prescribed by a doctor, other than vitamins?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

8. Is your child covered by some form of health insurance or other healthcare coverage?
    1. Yes
    2. No

8. Is your child covered by some form of health insurance or other healthcare coverage?
    7. Don't Know
    9. Refused

9. In the past 12 months, did you and your family have problems paying, or were unable to pay, for any of your child's medical bills?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

10. In the past 12 months, have you been frustrated in your efforts to obtain health care services for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

11. Is there a place that your child usually goes when [he/she] is sick or you need advice about [his/her] health?
    1. Yes [GO TO 12]
    2. No [SKIP TO 15]
    7. Don't Know [SKIP TO 15]
    9. Refused [SKIP TO 15]

12. What kind of place is it—a clinic, doctor's office, emergency room, or some other place?
    1. Clinic or health center
    2. Doctor's Office
    3. Hospital Emergency Room
    4. Hospital Outpatient Department
    5. Some other place
    6. Doesn't go to one place most often
    7. Don't Know
    9. Refused

13. Is this the same place that your child usually goes when [he/she] needs routine or preventive care such as a physical exam or well-child check-up?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

14. Is this the same place that you go when seeking advice about your child's vaccinations?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

15. During the past 12 months, was there any time when your child needed health care, but it was delayed or not received?
    1. Yes
    2. No
    7. Don't Know

15. During the past 12 months, was there any time when your child needed health care, but it was delayed or not received?
    9. Refused

16. What kind of place does your child usually go to when [he/she] needs routine or preventative care, such as a physical exam or well-child check-up?
    0. Doesn't get preventative care anywhere
    1. Clinic or health center
    2. Doctor's Office
    3. Hospital Emergency Room
    4. Hospital Outpatient Department
    5. Some other place
    6. Doesn't go to one place most often
    7. Don't Know
    9. Refused

17. How long have you known your child's doctor?
    1. [OPEN]
    7. Don't Know
    9. Refused

18. Do you have one or more persons you think of as your child's personal doctor or nurse?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

19. During the past 12 months, are you satisfied with the amount of time that your child's doctors and other health care providers spend with [him/her]?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

20. During the past 12 months, are you satisfied with how carefully your child's doctors and other health care providers listen to you?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

21. When your child is seen by doctors and other health care providers, are you satisfied with the level of sensitivity they showed to your family's values and customs?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

22. During the past 12 months, are you satisfied with the amount of information given from your child's doctors and other health care providers about your child's care?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

23. During the past 12 months, did you feel like a partner in your child's care by your child's doctors or other health care providers?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

24. During the past 12 months, are you satisfied with the quality of medical care provided to your child by your child's health care providers?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

25. During the past 12 months, are you satisfied with the range of options your child's doctors or other health care providers considered for your child's health care or treatment?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

26. During the past 12 months, did your child's doctors or other health care providers make it easy for you to raise concerns, ask questions, or disagree with recommendations for your child's health care?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

27. During the past 12 months, did your child's doctors or other health care providers work with you to decide together which health care treatments choices would be best for your child??
    1. Yes
    2. No
    7. Don't Know
    9. Refused

28. When you were selecting a doctor or health care provider for your child, was one of your considerations whether they would allow you to delay or refuse vaccines for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

29. Do you believe that your child's doctors or other health care providers have [his/her] best interests at heart?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

30. Have you or your child personally ever tried any alternative medicine, like herbal remedies, acupuncture, chiropractic, energy or other therapies?
    1. Yes
    2. No
    7. Don't Know

30. Have you or your child personally ever tried any alternative medicine, like herbal remedies, acupuncture, chiropractic, energy or other therapies?
    9. Refused

31. [If 1,7,9 to Q 30] The most recent time you used alternative medicine, did you use it instead of traditional medical treatments or in addition to traditional medical treatments?
    1. Instead of traditional medical treatments
    2. In addition to traditional medical treatments
    7. Don't Know
    9. Refused

Hesitancy

32. Do you trust the information you receive about shots??
    1. Yes
    2. No
    7. Don't Know
    9. Refused

33. Do you believe it is better for your child to develop immunity by getting sick than by getting a shot?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

34. Do you believe it is better for your child to get fewer shots at the same time?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

34a. Do you believe that children get more shots than are good for them?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

35. Overall, how hesitant about childhood shots would you consider yourself to be?
    1. Not at all hesitant
    2. Not that hesitant
    3. Unsure
    4. Somewhat hesitant
    5. Very hesitant
    9. Refused

36. Do you think that your child has received too many vaccines at one time?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

37. Do you think that your child receives too many vaccines?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

38. Do you think that your child's immune system would be overwhelmed by getting vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

39. Are you concerned with the volume of vaccines given to your child at one time?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

40. When making decisions to get your child vaccinated, were you concerned about emotional discomfort your child might experience during vaccination?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

41. When making decisions to get your child vaccinated, were you concerned about pain caused by the needle during the vaccine injection?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

42. When making decisions to get your child vaccinated, were you concerned about swelling at the injection site?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

43. When making decisions to get your child vaccinated, were you concerned about your child getting a fever or other illness after being vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

44. When making decisions to get your child vaccinated, were you concerned about the possibility of your child having a seizure?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

45. When making decisions to get your child vaccinated, were you concerned about long-term adverse side effects of the vaccine?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

46. When making decisions to get your child vaccinated, were you concerned about your child developing Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

47. When making decisions to get your child vaccinated, were you concerned about the ingredients of the vaccine?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

48. Has there ever been a time when you refused or decided not to get a vaccination for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

Confidence

49. Are you confident that all recommended childhood vaccines are safe for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

50. Are you confident that all recommended childhood vaccines protect your child from diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

51. Are you confident that all recommended childhood vaccines benefit your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

52. Are you confident that the Human papillomavirus, or HPV, vaccine is safe for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

53. Are you confident that the Human papillomavirus vaccine prevents your child from getting an HPV infection?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

54. Are you confident that the HPV vaccine can benefit your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

55. Are you confident that the annual flu shot is safe for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

56. Are you confident that the annual flu shot prevents your child from getting the flu?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

57. Are you confident that annual flu shot benefits your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

58. Overall, are you confident that vaccines you get for your child will prevent diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

59. Are you confident that childhood vaccines protect the general public from severe diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

60. Do you believe that serious reactions from childhood vaccines are rare?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

61. Do you believe that the benefits recommended vaccines provide your child outweigh their risks?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

62. Do you believe that recommended vaccines give your child the best protection from serious diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

63. Do you believe that vaccines are adequately tested for safety before they are administered to your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

64. Do you believe that vaccines strengthen your child's immune system?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

65. Do you believe that most vaccine side effects are minor, such as soreness at the spot where the shot was given or a low-grade fever?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

66. Do you believe that childhood vaccines prevent potentially deadly diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

67. Do you believe that there is a link between recommended childhood vaccines and the development of conditions such as autism?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

68. Do you believe that getting your child vaccinated helps protect others from getting disease?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

69. Do you believe that parents have an obligation to vaccinate their children?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

70. Do you believe that your child's immune system can handle several vaccines at one doctor's visit?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

Trust

71. Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]
    1. Your Child's Primary Care Doctor
    2. Your Primary Care Doctor
    3. Other Doctors Besides Your or Your Child's Primary Care Doctors

71. Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]

4. Nurses
5. Other Health Care Providers
6. Your Parents or Grandparents
7. Your Spouse or Partner
8. Your Peers
9. The Centers for Disease Control and Prevention (CDC) website
10. Your Local School System
11. Web Sites Such as WebMD
12. Parents' Message Boards and Other Similar Online Communities
13. The Centers for Disease Control and Prevention
14. Your Local Health Department
15 Other [Cognitive Testing Only]
97. Don't Know
99. Refused

71. Which of the following sources do you trust when making vaccination decisions for your child? [SELECT ALL THAT APPLY]

1. Your Child's Primary Care Doctor
2. Your Primary Care Doctor
3. Other Doctors Besides Your or Your Child's Primary Care Doctors
4. Nurses
5. Other Health Care Providers
6. Your Parents or Grandparents
7. Your Spouse or Partner
8. Your Peers
9. The Centers for Disease Control and Prevention (CDC) website
10. Your Local School System
11. Web Sites Such as WebMD
12. Parents' Message Boards and Other Similar Online Communities
13. The Centers for Disease Control and Prevention
14. Your Local Health Department
15 Other [Cognitive Testing Only]
97. Don't Know
99. Refused

73. Is information that your child's doctors or other health care professionals provide you about vaccines credible and trustworthy?

1. Yes
2. No
7. Don't Know
9. Refused

74. Is information that federal government agencies, such as the CDC, releases about vaccines and immunizations credible and trustworthy?

1. Yes
2. No
7. Don't Know
9. Refused

75. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from my doctor than from other sources

1. Agree
2. Disagree

75. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from my doctor than from other sources

3. Neither Agree or Disagree
7. Don't Know
9. Refused

76. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from the Centers for Disease Control and Prevention (CDC) than from other sources

1. Agree
2. Disagree
3. Neither Agree or Disagree
7. Don't Know
9. Refused

77. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from my family than from other sources.

1. Agree
2. Disagree
3. Neither Agree or Disagree
7. Don't Know
9. Refused

78. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I'm more likely to believe information about immunization safety that comes from something I've read than from other sources.

1. Agree
2. Disagree
3. Neither Agree or Disagree
7. Don't Know
9. Refused

79. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I trust recommended childhood vaccines that have been in use a long time more than I trust those that have recently become available.

1. Agree
2. Disagree
3. Neither Agree or Disagree
7. Don't Know
9. Refused

80. If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. Mostly supportive of vaccines
2. Neutral toward vaccines
3. Mostly unsupportive of vaccines
   I do not discuss vaccines with friends and family
7. Don't Know
9. Refused

Health Conditions and Side-Effects

81. Has a doctor or other healthcare provider ever told you that your child has allergies, including food, drug, or insect allergies?

1. Yes
2. No

81. Has a doctor or other healthcare provider ever told you that your child has allergies, including food, drug, or insect allergies?
    7. Don't Know
    9. Refused

82. Has a doctor or other healthcare provider ever told you that your child has blood disorders including sickle cell disease, thalassemia, or hemophilia?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

83. Has a doctor or other healthcare provider ever told you that your child has Down Syndrome?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

84. Has a doctor or other healthcare provider ever told you that your child has epilepsy or a seizure disorder?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

85. Has a doctor or other healthcare provider ever told you that your child has asthma?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

86. Has a doctor or other healthcare provider ever told you that your child has diabetes?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

87. Has a doctor or other healthcare provider ever told you that your child has pneumonia?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

88. Has a doctor or other healthcare provider ever told you that your child has the flu?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

89. Has a doctor or other healthcare provider ever told you that your child has Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

90. Has a doctor or other healthcare provider ever told you that your child has any health or medical condition that affected your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

91. Has your child ever had a side-effect from a vaccination?

1. Yes
2. No
7. Don't Know
9. Refused

92. Has your child ever had a serious reaction to a vaccination?

1. Yes
2. No
7. Don't Know
9. Refused

Appendix D: Round 2 Questionnaire

Outcome Section

1. Has your child received all, some, or none of the recommended vaccines to date?
    1. All of them
    2. Some of them
    3. None of them
    7. Don't Know
    9. Refused

2. During the past 12 months, has your child received a flu shot? A flu shot is usually given in the Fall and protects against influenza for the flu season.
    1. Yes
    2. No
    7. Don't Know
    9. Refused

3. How often does your child receive the annual influenza, or flu, shot?
    1. Every Year
    2. Some Years, but not Every Year
    3. Never
    7. Don't Know
    9. Refused

4. Has your child received a Human papillomavirus, or HPV, shot? [ONLY IF CHILD IS 10 AND OVER]
    1. Yes [SKIP to 6]
    2. No [GO TO 5]
    7. Don't Know [GO TO 5]
    9. Refused [GO TO 5]

5. [IF Q4=2,7, or 9] Are you planning for your child to receive the HPV shot in the future? [ONLY IF CHILD IS 10 AND OVER]
    1. Yes
    2. No
    7. Don't Know
    9. Refused

5a. Is your child administered vaccines following your pediatrician's recommended schedule, the CDC's recommended schedule, or some other schedule, such as the Sears Schedule?
    1. Pediatrician's Recommended Schedule
    2. CDC's Recommended Schedule
    3. Some Other Schedule
    7. Don't Know
    9. Refused

Perceived Needs and Access

6. In general, how would you describe your child's health?
    1. Excellent
    2. Very Good
    3. Good
    4. Fair
    5. Poor
    7. Don't Know
    9. Refused

9. In the past 12 months, did you and your family have problems paying, or were unable to pay, for any of your child's medical bills?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

11. Is there a place that your child usually goes when [he/she] is sick or you need advice about [his/her] health?
    1. Yes [GO TO 12]
    2. No [SKIP TO 15]
    7. Don't Know [SKIP TO 15]
    9. Refused [SKIP TO 15]

13. Is this the same place that your child usually goes when [he/she] needs routine or preventive care such as a physical exam or well-child check-up?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

14. Is this the same place that you go when seeking advice about your child's vaccinations?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

15. During the past 12 months, was there any time when your child needed health care, but it was delayed or not received?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

16. [IF NO TO Q13] What kind of place does your child usually go to when [he/she] needs routine or preventative care, such as a physical exam or well-child check-up?
    0. Doesn't get preventative care anywhere
    1. Clinic or health center
    2. Doctor's Office
    3. Hospital Emergency Room
    4. Hospital Outpatient Department
    5. Some other place
    6. Doesn't go to one place most often
    7. Don't Know
    9. Refused

17. How long have you known your child's doctor?
    1. [OPEN]
    7. Don't Know
    9. Refused

19. During the past 12 months, are you satisfied with the amount of time that your child's doctors and other health care providers spend with [him/her]?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

21. When your child is seen by doctors and other health care providers, are you satisfied with the level of sensitivity they showed to your family's values and customs?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

26. During the past 12 months, did your child's doctors or other health care providers make it easy for you to raise concerns, ask questions, or disagree with recommendations for your child's health care?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

28. When you were selecting a doctor or health care provider for your child, was one of your considerations whether they would allow you to delay or refuse vaccines for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

30. Have you personally ever tried any alternative medicine, like herbal remedies, acupuncture, chiropractic, energy or other therapies?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

31. [If 1,7,9 to Q 30] The most recent time you used alternative medicine, did you use it instead of traditional medical treatments or in addition to traditional medical treatments?
    1. Instead of traditional medical treatments
    2. In addition to traditional medical treatments
    7. Don't Know
    9. Refused

Hesitancy

32. Do you trust the information you receive about shots??
    1. Yes
    2. No
    7. Don't Know
    9. Refused

33. Do you believe it is better for your child to develop immunity by getting sick than by getting a shot?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

33a. Do you believe this is true for all diseases for which vaccines are available, or just some diseases for which vaccines are available?

1. All Diseases
2. Some Diseases
7. Don't Know
9. Refused

35. Overall, how hesitant about childhood shots would you consider yourself to be?

1. Not at all hesitant [SKIP TO 36]
2. Not that hesitant [GO TO 35a]

4. Somewhat hesitant [GO TO 35a]
5. Very hesitant [GO TO 35a]
3. Unsure
9. Refused

35a. [IF ANYTHING BUT 1 in Q35] Which of the following contribute to your hesitance?

1. Don't have enough information about certain vaccines
2. Don't have the ability to determine whether or not certain vaccines are safe
3. Don't know who to trust about vaccine safety and effectiveness
4. Don't know if your child actually needs all the recommended vaccines
5. Worried about specific ingredients in the recommended vaccines
6. Worried your child receives too many vaccines
7.. Worried about serious, long-term effects of the vaccination
8. Worried about minor, short-term effects of the vaccination
9. General concern about how your child reacts to medicines and shots
10. Never feel completely confident about any healthcare decisions for your child

36. Do you think that your child has received too many vaccines at one time?

1. Yes
2. No
7. Don't Know
9. Refused

37. Do you think that your child receives too many vaccines?

1. Yes
2. No
7. Don't Know
9. Refused

38a. Did concerns about whether your child's immune system would be overwhelmed impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

39a. Did concerns about the volume of vaccines given to your child at one time impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

40a. Did concerns about any emotional discomfort your child might experience during vaccination impact your decision to get [him/her] vaccinated??

1. Yes
2. No
7. Don't Know
9. Refused

41a. Did concerns about pain caused by the needle during the vaccine injection impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

42a. Did concerns about swelling at the injection site impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

43a. Did concerns about your child getting a fever or other illness after being vaccinated impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

44a. Did concerns about the possibility of your child having a seizure impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

45a. Did concerns about long-term adverse side effects of the vaccine impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

46a. Did concerns about your child developing Autism or an Autism Spectrum Disorder impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

47a. Did concerns the ingredients of the vaccine impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

48a. Has there ever been a time when you delayed or put off a vaccination for your child?

1. Yes

48a. Has there ever been a time when you delayed or put off a vaccination for your child?

2. No
7. Don't Know
9. Refused

48. Has there ever been a time when you refused or decided not to get a vaccination for your child?

1. Yes
2. No
7. Don't Know
9. Refused

Confidence

SET PROBE1. How confident are you that you have enough information to make vaccination decisions for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

SET PROBE2. How confident are you that you understand this information?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

49. How confident are you that all recommended childhood vaccines are safe for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

50. How confident are you that all recommended childhood vaccines lower your child's risk of disease?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

51. How confident are you that all recommended childhood vaccines benefit your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

52. How confident are you that the HPV vaccine is safe for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

53. How confident are you that the HPV vaccine prevents lowers your child's risk of getting an HPV infection?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

54. How confident are you that the HPV vaccine can benefit your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

55. How confident are you that the annual flu shot is safe for your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

56. How confident are you that the annual flu shot lowers your child's risk of getting the flu?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

57. How confident are you that annual flu shot benefits your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

58. Overall, how confident are you that vaccines lower your child's risk of getting diseases?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

59. How confident are you that childhood vaccines protect the general public from severe diseases?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

60. Do you believe that serious reactions from childhood vaccines are rare?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

61. Do you believe that the benefits recommended vaccines provide your child outweigh their risks?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

63. Do you believe that vaccines are adequately tested for safety before they are administered to your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

64. Do you believe that vaccines strengthen your child's immune system?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

65. Do you believe that most vaccine side effects are minor, such as soreness at the spot where the shot was given or a low-grade fever?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

66. Do you believe that childhood vaccines prevent potentially deadly diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

67. Do you believe that there is a link between recommended childhood vaccines and the development of conditions such as autism?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

68. Do you believe that getting your child vaccinated helps protect others from getting disease?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

69. Do you believe that parents have an obligation to vaccinate their children?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

70. Do you believe that your child's immune system can handle several vaccines at one doctor's visit?
    1. Yes
    2. No
    7. Don't Know

70. Do you believe that your child's immune system can handle several vaccines at one doctor's visit?
    9. Refused

Trust

71. Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]
    1. Your Child's Primary Care Doctor
    2. Your Primary Care Doctor
    3. Other Doctors Besides Your or Your Child's Primary Care Doctors
    4. Nurses
    5. Other Health Care Providers
    6. Your Parents or Grandparents
    7. Your Spouse or Partner
    8. Your Peers
    9. Government websites
    10. Your Local School System
    11. Web Sites Such as WebMD
    12. Parents' Message Boards and Other Similar Online Communities
    13. The Centers for Disease Control and Prevention
    14. Your Local Health Department
    15 Other [Cognitive Testing Only]
    97. Don't Know
    99. Refused

72. Which of the following sources do you trust when making vaccination decisions for your child? [SELECT ALL THAT APPLY]
    1. Your Child's Primary Care Doctor
    2. Your Primary Care Doctor
    3. Other Doctors Besides Your or Your Child's Primary Care Doctors
    4. Nurses
    5. Other Health Care Providers
    6. Your Parents or Grandparents
    7. Your Spouse or Partner
    8. Your Peers
    9. Government websites
    10. Your Local School System
    11. Web Sites Such as WebMD
    12. Parents' Message Boards and Other Similar Online Communities
    13. The Centers for Disease Control and Prevention
    14. Your Local Health Department
    15 Other [Cognitive Testing Only]
    97. Don't Know
    99. Refused

73. Is information that your child's doctors or other health care professionals provide you about vaccines credible and trustworthy?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

74. Is information that federal government agencies, such as the CDC, releases about vaccines and immunizations credible and trustworthy?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

79. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I trust recommended childhood vaccines that have been in use a long time more than I trust those that have recently become available.

1. Agree
2. Disagree
3. Neither Agree or Disagree
7. Don't Know
9. Refused

80. If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. Mostly supportive of vaccines
2. Neutral toward vaccines
3. Mostly unsupportive of vaccines
   I do not discuss vaccines with friends and family
7. Don't Know
9. Refused

Health Conditions and Side-Effects

81. Has a doctor or other healthcare provider ever told you that your child has allergies, including food, drug, or insect allergies?

1. Yes
2. No
7. Don't Know
9. Refused

82. Has a doctor or other healthcare provider ever told you that your child has blood disorders including sickle cell disease, thalassemia, or hemophilia?

1. Yes
2. No
7. Don't Know
9. Refused

83. Has a doctor or other healthcare provider ever told you that your child has Down Syndrome?

1. Yes
2. No
7. Don't Know
9. Refused

84. Has a doctor or other healthcare provider ever told you that your child has epilepsy or a seizure disorder?

1. Yes
2. No
7. Don't Know
9. Refused

85. Has a doctor or other healthcare provider ever told you that your child has asthma?

1. Yes
2. No
7. Don't Know
9. Refused

86. Has a doctor or other healthcare provider ever told you that your child has diabetes?

1. Yes
2. No
7. Don't Know

86. Has a doctor or other healthcare provider ever told you that your child has diabetes?
    9. Refused

87. Has a doctor or other healthcare provider ever told you that your child has pneumonia?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

88. Has a doctor or other healthcare provider ever told you that your child has the flu?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

89. Has a doctor or other healthcare provider ever told you that your child has Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

90. Has a doctor or other healthcare provider ever told you that your child has any health or medical condition that affected your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

91. Has your child ever had a side-effect from a vaccination?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

92. Has your child ever had a serious reaction to a vaccination?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

Appendix E: Round 3 Questionnaire

Outcome Section

1. Has your child received all, some, or none of the recommended vaccines to date?
    1. All of them
    2. Some of them
    3. None of them
    7. Don't Know
    9. Refused

2. During the past 12 months, has your child received a flu shot? A flu shot is usually given in the Fall and protects against influenza for the flu season.
    1. Yes
    2. No
    7. Don't Know
    9. Refused

3. How often does your child receive the annual influenza, or flu, shot?
    1. Every Year
    2. Some Years, but not Every Year
    3. Never
    7. Don't Know
    9. Refused

4. Has your child received a Human papillomavirus, or HPV, shot? [ONLY IF CHILD IS 10 AND OVER]
    1. Yes [SKIP to 6]
    2. No [GO TO 5]
    7. Don't Know [GO TO 5]
    9. Refused [GO TO 5]

5. [IF Q4=2,7, or 9] Are you planning for your child to receive the HPV shot in the future? [ONLY IF CHILD IS 10 AND OVER]
    1. Yes
    2. No
    7. Don't Know
    9. Refused

5a. Is your child administered vaccines following the Centers for Disease Control and Prevention, or CDC's recommended schedule, or some other schedule, such as the Sears Schedule?
    1. CDC's Recommended Schedule
    2. Some Other Schedule
    7. Don't Know
    9. Refused

Perceived Needs and Access

6. In general, how would you describe your child's health?
    1. Excellent
    2. Very Good
    3. Good
    4. Fair
    5. Poor
    7. Don't Know
    9. Refused

9. In the past 12 months, did you and your family have problems paying, or were unable to pay, for any of your child's medical bills?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

11. Is there a place that your child usually goes when [he/she] is sick or you need advice about [his/her] health?
    1. Yes [GO TO 12]
    2. No [SKIP TO 15]
    7. Don't Know [SKIP TO 15]
    9. Refused [SKIP TO 15]

13. Is this the same place that your child usually goes when [he/she] needs routine or preventive care such as a physical exam or well-child check-up?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

14. Is this the same place that you go when seeking advice about your child's vaccinations?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

15. During the past 12 months, was there any time when your child needed health care, but it was delayed or not received?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

16. [IF NO TO Q13] What kind of place does your child usually go to when [he/she] needs routine or preventative care, such as a physical exam or well-child check-up?
    0. Doesn't get preventative care anywhere
    1. Clinic or health center
    2. Doctor's Office
    3. Hospital Emergency Room
    4. Hospital Outpatient Department
    5. Some other place
    6. Doesn't go to one place most often
    7. Don't Know
    9. Refused

17. How long have you known your child's doctor?
    1. [OPEN]
    7. Don't Know
    9. Refused

19. During the past 12 months, are you satisfied with the amount of time that your child's doctors and other health care providers spend with [him/her]?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

21. When your child is seen by doctors and other health care providers, are you satisfied with the level of sensitivity they showed to your family's values and customs?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

26. During the past 12 months, did your child's doctors or other health care providers make it easy for you to raise concerns, ask questions, or disagree with recommendations for your child's health care?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

28. When you were selecting a doctor or health care provider for your child, was one of your considerations whether they would allow you to delay or refuse vaccines for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

30. Have you personally ever tried any alternative medicine, like herbal remedies, acupuncture, chiropractic, energy or other therapies?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

31. [If 1,7,9 to Q 30] The most recent time you used alternative medicine, did you use it instead of traditional medical treatments or in addition to traditional medical treatments?
    1. Instead of traditional medical treatments
    2. In addition to traditional medical treatments
    7. Don't Know
    9. Refused

Hesitancy

32. Do you trust the information you receive about shots??
    1. Yes
    2. No
    7. Don't Know
    9. Refused

33. Do you believe it is better for your child to develop immunity by getting sick than by getting a shot?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

33a. Do you believe this is true for all diseases for which vaccines are available, or just some diseases for which vaccines are available?

1. All Diseases
2. Some Diseases
7. Don't Know
9. Refused

35. Overall, how hesitant about childhood shots would you consider yourself to be?

1. Not at all hesitant [SKIP TO 36]
2. Not that hesitant [GO TO 35a]

4. Somewhat hesitant [GO TO 35a]
5. Very hesitant [GO TO 35a]
3. Unsure
9. Refused

35a. [IF ANYTHING BUT 1 in Q35] Which of the following contribute to your hesitance?

1. Don't have enough information about certain vaccines
2. Don't have the ability to determine whether or not certain vaccines are safe
3. Don't know who to trust about vaccine safety and effectiveness
4. Don't know if your child actually needs all the recommended vaccines
5. Worried about specific ingredients in the recommended vaccines
6. Worried your child receives too many vaccines
7.. Worried about serious, long-term effects of the vaccination
8. Worried about minor, short-term effects of the vaccination
9. General concern about how your child reacts to medicines and shots
10. Never feel completely confident about any healthcare decisions for your child

36. Do you think that your child has received too many vaccines at one time?

1. Yes
2. No
7. Don't Know
9. Refused

37. Do you think that your child receives too many vaccines?

1. Yes
2. No
7. Don't Know
9. Refused

38a. Did concerns about whether your child's immune system would be overwhelmed impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

39a. Did concerns about the volume of vaccines given to your child at one time impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

40a. Did concerns about any emotional discomfort your child might experience during vaccination impact your decision to get [him/her] vaccinated??

1. Yes
2. No
7. Don't Know
9. Refused

41a. Did concerns about pain caused by the needle during the vaccine injection impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

42a. Did concerns about swelling at the injection site impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

43a. Did concerns about your child getting a fever or other illness after being vaccinated impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

44a. Did concerns about the possibility of your child having a seizure impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

45a. Did concerns about long-term adverse side effects of the vaccine impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

46a. Did concerns about your child developing Autism or an Autism Spectrum Disorder impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

47a. Did concerns the ingredients of the vaccine impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

48a. Has there ever been a time when you delayed or put off a vaccination for your child?

1. Yes

48a. Has there ever been a time when you delayed or put off a vaccination for your child?

2. No
7. Don't Know
9. Refused

48. Has there ever been a time when you refused or decided not to get a vaccination for your child?

1. Yes
2. No
7. Don't Know
9. Refused

Confidence

SET PROBE1. How confident are you that you have enough information to make vaccination decisions for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

SET PROBE2. How confident are you that you understand this information?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

49. How confident are you that all recommended childhood vaccines are safe for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

50. How confident are you that all recommended childhood vaccines lower your child's risk of disease?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

51. How confident are you that all recommended childhood vaccines benefit your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

52. How confident are you that the HPV vaccine is safe for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

53. How confident are you that the HPV vaccine prevents lowers your child's risk of getting an HPV infection?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

54. How confident are you that the HPV vaccine can benefit your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

55. How confident are you that the annual flu shot is safe for your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

56. How confident are you that the annual flu shot lowers your child's risk of getting the flu?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

57. How confident are you that annual flu shot benefits your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

58. Overall, how confident are you that vaccines lower your child's risk of getting diseases?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

59. How confident are you that childhood vaccines protect the general public from severe diseases?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

60. Do you believe that serious reactions from childhood vaccines are rare?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

61. Do you believe that the benefits recommended vaccines provide your child outweigh their risks?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

63. Do you believe that vaccines are adequately tested for safety before they are administered to your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

64. Do you believe that vaccines strengthen your child's immune system?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

65. Do you believe that most vaccine side effects are minor, such as soreness at the spot where the shot was given or a low-grade fever?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

66. Do you believe that childhood vaccines prevent potentially deadly diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

67. Do you believe that there is a link between recommended childhood vaccines and the development of conditions such as autism?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

68. Do you believe that getting your child vaccinated helps protect others from getting disease?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

69. Do you believe that parents have an obligation to vaccinate their children?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

70. Do you believe that your child's immune system can handle several vaccines at one doctor's visit?
    1. Yes
    2. No
    7. Don't Know

70. Do you believe that your child's immune system can handle several vaccines at one doctor's visit?
    9. Refused

Trust

71. Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]
    1. Your Child's Primary Care Doctor
    2. Your Primary Care Doctor
    3. Other Doctors Besides Your or Your Child's Primary Care Doctors
    4. Nurses
    5. Other Health Care Providers
    6. Your Parents or Grandparents
    7. Your Spouse or Partner
    8. Your Peers
    9. Government websites
    10. Your Local School System
    11. Web Sites Such as WebMD
    12. Parents' Message Boards and Other Similar Online Communities
    13. The Centers for Disease Control and Prevention
    14. Your Local Health Department
    15 Other [Cognitive Testing Only]
    97. Don't Know
    99. Refused

73. Is information that your child's doctors or other health care professionals provide you about vaccines credible and trustworthy?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

74. Is information that federal government agencies, such as the CDC, releases about vaccines and immunizations credible and trustworthy?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

79. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I trust recommended childhood vaccines that have been in use a long time more than I trust those that have recently become available.
    1. Agree
    2. Disagree
    3. Neither Agree or Disagree
    7. Don't Know
    9. Refused

80. If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

    1. Mostly supportive of vaccines
    2. Neutral toward vaccines
    3. Mostly unsupportive of vaccines
       I do not discuss vaccines with friends and family
    7. Don't Know
    9. Refused

Health Conditions and Side-Effects

81. Has a doctor or other healthcare provider ever told you that your child has allergies, including food, drug, or insect allergies?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

82. Has a doctor or other healthcare provider ever told you that your child has blood disorders including sickle cell disease, thalassemia, or hemophilia?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

83. Has a doctor or other healthcare provider ever told you that your child has Down Syndrome?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

84. Has a doctor or other healthcare provider ever told you that your child has epilepsy or a seizure disorder?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

85. Has a doctor or other healthcare provider ever told you that your child has asthma?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

86. Has a doctor or other healthcare provider ever told you that your child has diabetes?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

87. Has a doctor or other healthcare provider ever told you that your child has pneumonia?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

88. Has a doctor or other healthcare provider ever told you that your child has the flu?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

89. Has a doctor or other healthcare provider ever told you that your child has Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?
    1. Yes
    2. No
    7. Don't Know

89. Has a doctor or other healthcare provider ever told you that your child has Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?
    9. Refused

90. Has a doctor or other healthcare provider ever told you that your child has any health or medical condition that affected your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

91. Has your child ever had a side-effect from a vaccination?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

92. Has your child ever had a serious reaction to a vaccination?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

Appendix F: Round 4 Questionnaire

1. Has your child received all, some, or none of the recommended vaccines to date?
    1. All of them
    2. Some of them
    3. None of them
    7. Don't Know
    9. Refused

SHORT SET

5b. Is your child administered vaccines following a standard schedule, or some other schedule, such as the Sears Schedule?
    1. Standard schedule
    2. Some other schedule
    7. Don't Know
    9. Refused

35. Overall, how hesitant about childhood shots would you consider yourself to be?
    1. Not at all hesitant
    2. Not that hesitant
    4. Somewhat hesitant
    5. Very hesitant
    3. Unsure
    9. Refused

48a. Has there ever been a time when your concerns about childhood shots caused you to spread out or delay vaccinations for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

48. Has there ever been a time when your concerns about childhood shots caused you to refuse or decide not to get a vaccination for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

28. When you were selecting a doctor or health care provider for your child, was one of your considerations whether they would allow you to delay or refuse vaccines for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

100. When you were selecting a doctor or health care provider for your child, did you look for a provider who would follow the standard vaccination schedule?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

36. Did concerns about the number of vaccines your child gets at one time impact your decision to get your child vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

39a. Did concerns about the amount of medicine in the shots impact your decision to get your child vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

45a. Did concerns about serious, long-term side effects impact your decision to get your child vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

101. How confident are you that all of the vaccines your child's doctor recommended so far are necessary?

1. Very confident
2. Somewhat confident
3. Not at all confident
7. Don't Know
9. Refused

49a. How confident are you that all recommended childhood vaccines are safe for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

61. How confident are you that the benefits of vaccines outweigh their risks?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

102. Do you personally know anyone who has had a serious, long-term side effect from a vaccine?

1. Yes
2. No
7. Don't Know
9. Refused

90. Has a doctor or other healthcare provider ever told you that your child has any health or medical condition that affected your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

80. If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. Mostly supportive
2. Mostly neutral
3. Mostly unsupportive
4. Mixed – that is, both supportive and unsupportive of vaccines
   I do not discuss vaccines with friends and family
7. Don't Know
9. Refused

103. Is your child's doctor or health provider your most trusted source of information about childhood vaccines?

1. Yes
2. No
7. Don't Know
9. Refused

Outcome Section

2. During the past 12 months, has your child received a flu shot? A flu shot is usually given in the Fall and protects against influenza for the flu season.

1. Yes
2. No
7. Don't Know
9. Refused

3. How often does your child receive the annual influenza, or flu, shot?

1. Every Year
2. Some Years, but not Every Year
3. Never
7. Don't Know
9. Refused

4. [ONLY IF CHILD IS 10 AND OVER]Has your child received a Human papillomavirus, or HPV, shot?

1. Yes [SKIP to 6]
2. No [GO TO 5]
7. Don't Know [GO TO 5]
9. Refused [GO TO 5]

5. [ONLY IF CHILD IS 10 AND OVER] [IF Q4=2,7, or 9] Are you planning for your child to receive the HPV shot in the future?

1. Yes
2. No
7. Don't Know
9. Refused

Perceived Needs and Access

6. In general, how would you describe your child's health?

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor
7. Don't Know
9. Refused

9. In the past 12 months, did you and your family have problems paying, or were unable to pay for any of your child's medical bills?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

11. Is there a place that your child usually goes when [he/she] is sick or you need advice about [his/her] health?
    1. Yes [GO TO 13]
    2. No [SKIP TO 15]
    7. Don't Know [SKIP TO 15]
    9. Refused [SKIP TO 15]

13. Is this the same place that your child usually goes when [he/she] needs routine or preventive care such as a physical exam or well-child check-up?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

14. Is this the same place that you go when seeking advice about your child's vaccinations?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

15. During the past 12 months, was there any time when your child needed health care, but it was delayed or not received?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

16. [IF NO TO Q13] What kind of place does your child usually go to when [he/she] needs routine or preventative care, such as a physical exam or well-child check-up?
    0. Doesn't get preventative care anywhere
    1. Clinic or health center
    2. Doctor's Office
    3. Hospital Emergency Room
    4. Hospital Outpatient Department
    5. Some other place
    6. Doesn't go to one place most often
    7. Don't Know
    9. Refused

17. How long have you known your child's doctor?
    1. [OPEN]
    7. Don't Know
    9. Refused

19. During the past 12 months, are you satisfied with the amount of time that your child's doctors and other health care providers spend with [him/her]?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

21. When your child is seen by doctors and other health care providers, are you satisfied with the level of sensitivity they showed to your family's values and customs?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

26. During the past 12 months, did your child's doctors or other health care providers make it easy for you to raise concerns, ask questions, or disagree with recommendations for your child's health care?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

30. Have you personally ever tried any alternative medicine, like herbal remedies, acupuncture, chiropractic, energy or other therapies?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

31. [If 1,7,9 to Q 30] The most recent time you used alternative medicine, did you use it instead of traditional medical treatments or in addition to traditional medical treatments?
    1. Instead of traditional medical treatments
    2. In addition to traditional medical treatments
    7. Don't Know
    9. Refused

Hesitancy

32. Do you trust the information you receive about shots??
    1. Yes
    2. No
    7. Don't Know
    9. Refused

33a1. Do you believe it is better for your child to develop immunity by getting sick or by getting a shot?
    1. Getting sick
    2. Getting a shot
    7. Don't Know
    9. Refused

33a. Do you believe this is true for all diseases for which vaccines are available, or just some diseases for which vaccines are available?
    1. All Diseases
    2. Some Diseases
    7. Don't Know
    9. Refused

37. Do you think that your child receives too many vaccines?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

38a. Did concerns about whether your child's immune system would be overwhelmed impact your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

40a. Did concerns about any emotional discomfort your child might experience during vaccination impact your decision to get [him/her] vaccinated??
    1. Yes
    2. No
    7. Don't Know
    9. Refused

41a. Did concerns about pain caused by the needle during the vaccine injection impact your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

42a. Did concerns about swelling at the injection site impact your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

43a. Did concerns about your child getting a fever or other illness after being vaccinated impact your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

44a. Did concerns about the possibility of your child having a seizure impact your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

46a. Did concerns about your child developing Autism or an Autism Spectrum Disorder impact your decision to get [him/her] vaccinated?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

47a. Did concerns about the ingredients of the vaccine impact your decision to get [him/her] vaccinated?
    1. Yes
    2. No

47a. Did concerns about the ingredients of the vaccine impact your decision to get [him/her] vaccinated?

7. Don't Know
9. Refused

Confidence

SET PROBE1. How confident are you that you have enough information to make vaccination decisions for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

SET PROBE2. How confident are you that you understand this information?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

50a. How confident are you that all recommended childhood vaccines lower your child's risk of disease?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

51a. How confident are you that all recommended childhood vaccines benefit your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

52a. How confident are you that the HPV vaccine is safe for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

53. How confident are you that the HPV vaccine lowers your child's risk of getting an HPV infection?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

54. How confident are you that the HPV vaccine can benefit your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

55. How confident are you that the annual flu shot is safe for your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

56. How confident are you that the annual flu shot lowers your child's risk of getting the flu?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

57. How confident are you that annual flu shot benefits your child?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

58. Overall, how confident are you that vaccines lower your child's risk of getting diseases?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

59. How confident are you that childhood vaccines protect the general public from severe diseases?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    7. Don't Know
    9. Refused

60. Do you believe that serious reactions from childhood vaccines are rare?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

63. Do you believe that vaccines are adequately tested for safety before they are administered to your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

64. Do you believe that vaccines strengthen your child's immune system?
    1. Yes
    2. No
    7. Don't Know

64. Do you believe that vaccines strengthen your child's immune system?
    9. Refused

65. Do you believe that most vaccine side effects are minor, such as soreness at the spot where the shot was given or a low-grade fever?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

66. Do you believe that childhood vaccines prevent potentially deadly diseases?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

67. Do you believe that there is a link between recommended childhood vaccines and the development of conditions such as autism?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

68. Do you believe that getting your child vaccinated helps protect others from getting disease?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

69. Do you believe that parents have an obligation to vaccinate their children?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

70. Do you believe that your child's immune system can handle several vaccines at one doctor's visit?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

Trust

71. Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]
    1. Your Child's Primary Care Doctor
    2. Your Primary Care Doctor
    3. Other Doctors Besides Your or Your Child's Primary Care Doctors
    4. Nurses
    5. Other Health Care Providers
    6. Your Parents or Grandparents
    7. Your Spouse or Partner

71. Which of the following sources have you consulted when making vaccination decisions for your child? [SELECT ALL THAT APPLY]
    8. Your Peers
    9. Government websites
    10. Your Local School System
    11. Web Sites Such as WebMD
    12. Parents' Message Boards and Other Similar Online Communities
    13. The Centers for Disease Control and Prevention
    14. Your Local Health Department
    15 Other [Cognitive Testing Only]
    97. Don't Know
    99. Refused

73. Is information that your child's doctors or other health care professionals provide you about vaccines credible and trustworthy?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

74. Is information that federal government agencies, such as the CDC, releases about vaccines and immunizations credible and trustworthy?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

79. Please indicate whether or not you agree, disagree, or neither agree or disagree with the following statements: I trust recommended childhood vaccines that have been in use a long time more than I trust those that have recently become available.
    1. Agree
    2. Disagree
    3. Neither Agree or Disagree
    7. Don't Know
    9. Refused

Health Conditions and Side-Effects

81. Has a doctor or other healthcare provider ever told you that your child has allergies, including food, drug, or insect allergies?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

82. Has a doctor or other healthcare provider ever told you that your child has blood disorders including sickle cell disease, thalassemia, or hemophilia?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

83. Has a doctor or other healthcare provider ever told you that your child has Down Syndrome?
    1. Yes
    2. No
    7. Don't Know

83. Has a doctor or other healthcare provider ever told you that your child has Down Syndrome?
    9. Refused

84. Has a doctor or other healthcare provider ever told you that your child has epilepsy or a seizure disorder?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

85. Has a doctor or other healthcare provider ever told you that your child has asthma?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

86. Has a doctor or other healthcare provider ever told you that your child has diabetes?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

87. Has a doctor or other healthcare provider ever told you that your child has pneumonia?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

88. Has a doctor or other healthcare provider ever told you that your child has the flu?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

89. Has a doctor or other healthcare provider ever told you that your child has Autism or an Autism Spectrum Disorder, including Asperger's Syndrome and Pervasive Developmental Disorder?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

92. Has your child ever had a serious reaction to a vaccination?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

91. Has your child ever had a side-effect from a vaccination?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

Appendix G: Round 5 Questionnaire

1. Has your child received all, some, or none of the recommended vaccines to date?
    1. All of them
    2. Some of them
    3. None of them
    7. Don't Know
    9. Refused

5b. Is your child administered vaccines following a standard schedule, or some other schedule, such as the Sears Schedule?
    1. Standard schedule
    2. Some other schedule
    7. Don't Know
    9. Refused

35. Overall, how hesitant about childhood shots would you consider yourself to be?
    1. Not at all hesitant
    2. Not that hesitant
    4. Somewhat hesitant
    5. Very hesitant
    3. Unsure
    9. Refused

48a. Has there ever been a time when your concerns about childhood shots caused you to spread out or delay vaccinations for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

48. Has there ever been a time when your concerns about childhood shots caused you to refuse or decide not to get a vaccination for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

28. When you were selecting a doctor or health care provider for your child, was one of your considerations whether they would allow you to delay or refuse vaccines for your child?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

100. When you were selecting a doctor or health care provider for your child, did you actively look for a provider who would follow the standard vaccination schedule?
    1. Yes
    2. No
    7. Don't Know
    9. Refused

36. Did concerns about the number of vaccines your child gets at one time impact your decision to get your child vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

38a. Did concerns about whether your child's immune system would be overwhelmed impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

39a1. Did concerns about the amount of medicine in the shots impact your decision to get your child vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

45a. Did concerns about serious, long-term side effects impact your decision to get your child vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

47a. Did concerns about the ingredients of the vaccine impact your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

51a. How confident are you that all recommended childhood vaccines benefit your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

101. How confident are you that all of the vaccines your child's doctor recommended so far are necessary?

1. Very confident
2. Somewhat confident
3. Not at all confident
7. Don't Know
9. Refused

49a. How confident are you that all recommended childhood vaccines are safe for your child?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident

49a. How confident are you that all recommended childhood vaccines are safe for your child?

7. Don't Know
9. Refused

58a. Overall, how confident are you that vaccines lower your child's risk of getting diseases?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

61a. How confident are you that the benefits of vaccines outweigh their risks?

1. Very Confident
2. Somewhat Confident
3. Not at all Confident
7. Don't Know
9. Refused

102. Do you personally know anyone who has had a serious, long-term side effect from a vaccine?

1. Yes
2. No
7. Don't Know
9. Refused

63. Do you believe that vaccines are adequately tested for safety before they are administered to your child?

1. Yes
2. No
7. Don't Know
9. Refused

67. Do you believe that there is a link between recommended childhood vaccines and the development of conditions such as autism?

1. Yes
2. No
7. Don't Know
9. Refused

68. Do you believe that getting your child vaccinated helps protect others from getting disease?

1. Yes
2. No
7. Don't Know
9. Refused

69. Do you believe that parents have an obligation to vaccinate their children?

1. Yes
2. No
7. Don't Know
9. Refused

90. Has a doctor or other healthcare provider ever told you that your child has any health or medical condition that affected your decision to get [him/her] vaccinated?

1. Yes
2. No
7. Don't Know
9. Refused

80. If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. Mostly positive
3. Mostly negative
4. Mixed—that is, both positive and negative
2. Mostly Neutral
   I do not discuss vaccines with friends and family
7. Don't Know
9. Refused

103. Is your child's doctor or health provider your most trusted source of information about childhood vaccines?

1. Yes
2. No
7. Don't Know
9. Refused

Appendix H: Final Questionnaire

CHILDHOOD VACCINATION HESITANCY AND ACCEPTANCE QUESTIONNAIRE (CVHAQ-DRAFT)

Green questions=1, 3 and 5 minute sets
Non-highlighted questions=3 and 5 minute sets
Yellow questions=5 minute set only
[Note that answer categories in *italics* are not administered to respondents]

1. Is your child administered vaccines following a standard schedule, or some other schedule?
    1. Standard schedule
    2. Some other schedule
    -7. *Don't Know*
    -9. *Refused*

2. Overall, how hesitant about childhood shots would you consider yourself to be?
    1. Not at all hesitant
    2. Not that hesitant
    4. Somewhat hesitant
    5. Very hesitant
    -7. *Unsure*
    -9. *Refused*

3. Has there ever been a time when your concerns about childhood shots caused you to spread out or delay vaccinations for your child?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

4. Has there ever been a time when your concerns about childhood shots caused you to refuse or decide not to get a vaccination for your child?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

5. When you were selecting a doctor or health care provider for your child, was one of your considerations whether they would allow you to delay or refuse vaccines for your child?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

6. When you were selecting a doctor or health care provider for your child, did you actively look for a provider who would follow the standard vaccination schedule?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

7. Did concerns about the number of vaccines your child gets at one time impact your decision to get your child vaccinated?
   1. Yes
   2. No
   -7. *Don't Know*
   -9. *Refused*

8. Did concerns about whether your child's immune system would be overwhelmed impact your decision to get [him/her] vaccinated?
   1. Yes
   2. No
   -7. *Don't Know*
   -9. *Refused*

9. Did concerns about the amount of medicine in the shots impact your decision to get your child vaccinated?
   1. Yes
   2. No
   -7. *Don't Know*
   -9. *Refused*

10. Did concerns about serious, long-term side effects impact your decision to get your child vaccinated?
   1. Yes
   2. No
   -7. *Don't Know*
   -9. *Refused*

11. Did concerns about the ingredients of the vaccine impact your decision to get [him/her] vaccinated?
   1. Yes
   2. No
   -7. *Don't Know*
   -9. *Refused*

12. How confident are you that all recommended childhood vaccines benefit your child?
   1. Very Confident
   2. Somewhat Confident
   3. Not at all Confident
   -7. *Don't Know*
   -9. *Refused*

13. How confident are you that all of the vaccines your child's doctor recommended so far are necessary?
   1. Very confident
   2. Somewhat confident
   3. Not at all confident
   -7. *Don't Know*
   -9. *Refused*

14. How confident are you that all recommended childhood vaccines are safe for your child?
   1. Very Confident

14. How confident are you that all recommended childhood vaccines are safe for your child?
    2. Somewhat Confident
    3. Not at all Confident
    -7. *Don't Know*
    -9. *Refused*

15. Overall, how confident are you that vaccines lower your child's risk of getting diseases?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    -7. *Don't Know*
    -9. *Refused*

16. How confident are you that the benefits of vaccines outweigh their risks?
    1. Very Confident
    2. Somewhat Confident
    3. Not at all Confident
    -7. *Don't Know*
    -9. *Refused*

17. Do you personally know anyone who has had a serious, long-term side effect from a vaccine?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

18. Do you believe that vaccines are adequately tested for safety before they are administered to your child?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

19. Do you believe that there is a link between recommended childhood vaccines and the development of conditions such as autism?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

20. Do you believe that getting your child vaccinated helps protect others from getting disease?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

21. Do you believe that parents have an obligation to vaccinate their children?
    1. Yes
    2. No
    -7. *Don't Know*
    -9. *Refused*

22. Has a doctor or other healthcare provider ever told you that your child has any health or medical condition that affected your decision to get [him/her] vaccinated?

1. Yes
2. No
-7. *Don't Know*
-9. *Refused*

23. If you ever discuss childhood vaccines with friends and family, would you say those discussions are…

1. Mostly positive
3. Mostly negative
4. Mixed—that is, both positive and negative
2. Mostly Neutral
   I do not discuss vaccines with friends and family
-7. *Don't Know*
-9. *Refused*

24. Is your child's doctor or health provider your most trusted source of information about childhood vaccines?

1. Yes
2. No
-7. *Don't Know*
-9. *Refused*