Mental Models

Interview Protocol and Technique

Vaccine Risk Communication
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong></td>
<td>3</td>
</tr>
<tr>
<td>Development of Tentative Model on Vaccination Risk Communication</td>
<td>3</td>
</tr>
<tr>
<td>Structure of Interview Protocol</td>
<td>12</td>
</tr>
<tr>
<td>Analyses and Applications</td>
<td>14</td>
</tr>
<tr>
<td><strong>Vaccine Mental Models Interviews</strong></td>
<td>16</td>
</tr>
<tr>
<td>Screening Interview</td>
<td>16</td>
</tr>
<tr>
<td>Recruitment Log for Vaccine Interviews</td>
<td>18</td>
</tr>
<tr>
<td>Interview Protocol</td>
<td>20</td>
</tr>
<tr>
<td>Quantitative Data Log for Vaccine Interviews</td>
<td>40</td>
</tr>
<tr>
<td><strong>Interviewer Hints</strong></td>
<td>41</td>
</tr>
<tr>
<td>Attitude</td>
<td>41</td>
</tr>
<tr>
<td>Mechanics</td>
<td>42</td>
</tr>
<tr>
<td><strong>Instructions to Transcribers</strong></td>
<td>44</td>
</tr>
<tr>
<td>Format</td>
<td>44</td>
</tr>
<tr>
<td>Procedures</td>
<td>44</td>
</tr>
<tr>
<td><strong>Next Steps</strong></td>
<td>46</td>
</tr>
<tr>
<td>Coding of the Transcribed Interviews</td>
<td>47</td>
</tr>
<tr>
<td>Expert Model from Herpes and Stigma Project</td>
<td>48</td>
</tr>
<tr>
<td>Interview Coding Sheet from Herpes and Stigma Project</td>
<td>49</td>
</tr>
<tr>
<td>Development of Targeted Intervention</td>
<td>50</td>
</tr>
</tbody>
</table>
Background

Development of tentative model on vaccination risk communication

Based on consultation with experts, an influence diagram was formulated, representing the processes that affect vaccination rates, and the associated disease risk (see Figure 1). In this representation, each oval node is a variable in the decision space. Arrows mean that the variable at the tail of the arrow has some power to predict the variable at the tip of the arrow; that relationship could be causal. We now walk through the figure, using the identifying letter in each node, beginning in the upper left corner of the model.

Public health strategy and plans (node g) represent an agency working to protect public health. These lead to a vaccine program (node d). Having two separate nodes recognizes the fact that plans can have many practical expressions. Program features that influence coverage include scope (does it cover children, soldiers, other groups?), incentives (do schools require it?), and protection (e.g., does the government protect vaccine companies from legal action, in order to promote production?).

Knowing the program’s design facilitates predicting vaccine coverage (node v). The coverage also depends on people's individual assessments of the vaccine’s risks and benefits (node r). Vaccine coverage has a non-linear relationship with general population immunity, sometimes called herd immunity (node i). Better immunity lowers
the potential for an outbreak (node o), as fewer people can serve as disease vectors. Immunity and outbreak potential together predict population health (node p).

Figure 1: Simple MMR Vaccine Decision Model

By definition, disease threat (node t) affects population health; the more prevalent the disease, the more people will get it. Disease threat also affects assessments of vaccine benefit; the more disease that is present, the more valuable the vaccine seems.

Figure 2 adds potential negative effects of vaccination (link vp), leading to poorer population health (than if adverse effects never occurred). These increase with the
number of people getting vaccines. When adverse effects are observed, especially potential new ones, they must be *reported and tracked* (node z). Over time, tracking these trends in population health facilitates determining whether vaccines are involved (and taking subsequent action).

**Figure 2: MMR Vaccine Decision Model: Harm From Vaccines**

Figure 3 shows some of the indicators that may influence such tracking. These include how well reactions are *identified* (node y) and *treated* (node a) – with treatment having direct effects on population health (as well as the indirect effects of improving the vaccination program). If a child has a fever after vaccination (link vy), one can try to
lower the fever (link ya), thereby preventing possible febrile seizures (link ap) that could cause damage (link vp). One might also decide that a child is particularly sensitive to the vaccine, and forgo the next dose (link yr).

Figure 3: MMR Vaccine Decision Model: Identify Harm From Vaccines

Keeping track of health effects can affect education programs (node e) that inform parents’ assessments of risks (link er) and benefits (link eb). Those programs might come from supporters of vaccination (e.g., a CDC statement warning against additional doses for children who have had a bad reaction) or opponents (e.g., web sites promulgating case reports). Obviously, the effect of such programs will depend on their content, distribution, and persuasiveness. The term “education” is used for all such efforts, without judging their accuracy.
Figure 4 expands on the effects of vaccine safety research (node $k$). As possible adverse events come to light, they might provoke dedicated studies (link $gk$). Study results should improve vaccine risk estimates (link $kr$). They may also reduce actual risks by changing vaccine quality (link $kq$), such as by removing thimerosal from vaccines or using acellular Pertussis. That, in turn, should affect risk perceptions (link $qr$).

Figure 4: MMR Vaccine Decision Model: Address Harm From Vaccines

Figure 5 shows other processes affecting vaccination programs. Pharmaceutical companies must make the vaccine available (node $f$). Their ability to do so depends on the supply (node $c$) and quality of ingredients (node $q$). The allocation of vaccine depends on the screening policy (node $s$), which depends on medical understanding of health.
risks and vaccine availability (e.g., only vaccinating high-risk individuals until supplies recover). For example, CDC recently announced a shortage of tetanus and diphtheria vaccine, because one company had stopped making the vaccine. CDC deferred, by a year, immunization for students who normally require it for school enrollment. Thus, the screening protocol affects the vaccination program’s total coverage (link $sv$).

Figure 5: MMR Vaccine Decision Model: Availability and Quality of Vaccines

The quality of the vaccine determines its effectiveness (node $n$), which, in turn, affects herd immunity (link $ni$), as does total vaccination coverage (link $vi$).
Figure 6 shows additional factors affecting perceptions of risk and benefit, in addition to “educational messages” about vaccines. One, often important, source is health care providers (node h), themselves potentially influenced by education (link eh). Trust (or distrust) in the public health community (node u) may affect beliefs about the safety of vaccines (link ur) or about their benefits (link ub). The credibility of the public health system can also affect the effectiveness of health care providers’ communications (link uh).

Individuals’ personal values (node m) can affect their assessment of risks (link mr) and benefits (link mb), but especially the decision to vaccinate independent of a risk/benefit assessment (link mv). For example, libertarians may not want the
government telling them what to do, no matter how they view the risk-benefit tradeoffs. A principled desire to protect others (e.g., by improving herd immunity, in the population as a whole or for one’s immediate associates) could override risk-benefit concerns. For example, a husband might get vaccinated, just because his pregnant wife could not.

Figure 7 presents the full model developed for this research, adding several program-level considerations. One is that the results of disease tracking (node $l$) can lead to changes in screening protocols (as when greater prevalence leads to expanded programs). Policies that lead to multiple vaccines (link $dx$) may affect perceptions of safety (link $xr$). Perceptions of vaccine safety can affect dosages (e.g., skipping later doses after an apparent side effect, link $rj$), which then affect overall effectiveness (link $jn$).
Overall public health strategies can be affected by feedback regarding the potential for outbreaks and the prevalence of adverse events (link zg). Reports of adverse events sometimes prompt new research (link gk). Increased outbreak potential can spur new vaccine programs; drastically reduced potential may justify discontinuing a vaccine (link og).

The "expert model" of Figure 7 is intended to circumscribe the medical and social factors determining the population health achieved by a vaccination program. Were the research base available, its variables (nodes) and functional relationships (links) could be estimated for specific circumstances and the effectiveness of alternative programs predicted. For the purposes of vaccine risk communication, a formal, but qualitative model suffices to guide the interviewing process and analyses of respondents’ communications. If quantitative predictions were sought, interviews could also elicit requisite parameter estimates (e.g., the percentage of individuals with overriding objections to compulsory vaccination).

The interview protocol following this expert model directs respondents to all its topic areas, with increasingly directive prompts. The data analysis codes those responses into them, preserving the prompts (so that one can tell what spontaneous views are). Responses are coded into the expert model, as a way of characterizing lay
views in a common framework that is relevant to the success of vaccination programs. This interview and coding process reveals the mental models of participants. Before describing it, we will look at the mental models revealed in communications developed by supporters and opponents of vaccination.

**Structure of Interview Protocol**

In order to clarify the current state of lay understanding and guide the development of future communications, we plan to conduct interviews with new parents around the country, eliciting their beliefs the risks and benefits of vaccines and the processes shaping their decisions. The interviews will conclude by having them evaluate the persuasiveness of communications, crossing the dimensions described above. The development of the interview protocol followed our general research procedure, guided by the expert model and the mental models revealed in various sources (including communications like those accessed through the CDCNIP database). As the second phase of the project begins, the draft protocol may be refined through pretest interviews with individuals drawn from the target population.

When scheduling the interview, parents will be asked a few basic questions, identifying their opinion about vaccine safety and public health in general. These questions will help us to select a pool of respondents that over-samples individuals somewhat distrustful of vaccines and government recommendations. Because these
people are likely to be over-represented in the target audience of future vaccination safety communications, their opinions are critical to this research.

The draft interview protocol begins broadly, asking respondents to describe how vaccines work, with a prompt to consider the question at a population level. This question, before any broader descriptions, is aimed at assessing whether respondents have a basic working knowledge of antibodies and herd immunity. Following this general start, respondents are asked about their own children and vaccination decisions. These questions begin with a general probe of the parents’ concerns (if any) about vaccination, asking separately about risks and benefits, then turning to their children's personal experiences with vaccination. The next section of the protocol covers the kinds of information that respondents have sought and received about vaccination, including its sources. The protocol then asks respondents to evaluate specific vaccination decisions made by hypothetical parents.

Having established the factors relevant to the respondent's vaccination decisions, the protocol turns to the evaluation of sample communications. A communication will be read aloud to the respondent, followed by questions focusing on its content and persuasiveness, including how they believe it would affect a generic parent's vaccination decision, and their own. There are eight communications, each quite short (under 250 words), representing one cell in a 2 x 2 x 2 crossed design with the factors of position (pro- vs. anti-vaccine), evidence (statistical vs. anecdotal), and structure (linked vs. directed). Each respondent will hear 2 stories representing opposite cells on each
dimension. For example, if the first story is anti-vaccine, with statistical evidence and a directed structure, the second will be pro-vaccine, with anecdotal evidence and a linked structure. Aggregating across respondents, it will be possible to disentangle the three factors to measure the impact of each on persuasiveness.

Finally, demographic information will be obtained, and the respondent will be given the opportunity to provide any other thoughts, ask any questions about vaccination, or offer any advice to CDC.

**Analyses and Applications**

The interviews will be transcribed verbatim. The transcripts will be divided into separate statements, each of which will be coded into the expert model. These codes will be analyzed to characterize parents' mental models of vaccination in terms that can be compared to the expert model, hence direct future communications.

Further analyses will concern the relationship between parents' mental models and the concepts communicated by different agencies, especially in light of which sources of information parents report having consulted in forming their beliefs and reaching their decisions. This approach will be enlightened by the analysis of the communication evaluation portion of the interviews. Responsiveness to the three dimensions of communication will be related to mental models by different groups of parents, including those that more and less hostile to vaccination, and to public health in general.
This research will reveal parents’ patterns of reasoning and response to vaccination risk communication, providing both their mental models of vaccine risk and guidelines for future communications. In the communications emerging from this project, we will draw on the expert model (identifying decision-critical information), mental models interviews (identifying lay information needs), and the general research literature on risk communications.
Vaccine Mental Models Interviews

This section concerns the specific protocol and procedures for conducting mental models interviews about vaccination.

**Bold** text is intended to help guide the interviewer; do not read bold text to interviewee. Questions in **red** are intended to elicit quantitative responses, rather than explicative responses. Phrases in [brackets] are meant to be replaced with particular identifying information given by the interviewee, such as replacing [this person] with "your doctor" if they had mentioned their doctor in the context of the question, or replacing [your first child] with the name they have given. Occasionally a prompt is provided, to clarify a question if the interviewee doesn’t appear to understand, or if their answer does not seem appropriate.

The screening interview will be conducted in advance, to select the desired sample, and to give the interviewee a chance to read and sign the consent form, and to find their child's vaccination records before the interview.

In the interview protocol, question numbers are provided to help structure the interview. However, please do not read these question numbers.

**Screening Interview**

*Hello, may I speak to [name of parent(s)] please? Hi, this is [your name here], with Carnegie Mellon University and Oak Ridge Associated Universities, and I'm calling to ask if you would like to participate in a paid telephone interview for a research project that concerns your thoughts about vaccination of your child. May I tell you a bit about this interview? [if no: Thank you for your time, sorry to bother you. Hang up.]*
Thank you. I am working on a research project that looks at perceptions of the benefits and safety of childhood vaccination, and explores how parents make decisions about vaccinating their children. We received your name from [where?], which indicated that you have a child between 18 and 23 months of age, a time when many vaccines are recommended. May I ask you a few questions to determine whether you are eligible for this interview?

- How many children do you have living with you at this time?
- Can you tell me your children’s ages and whether each is male or female?

[if oldest child not aged 18-23 months] I’m sorry, but we are looking for people whose oldest child is between 18 and 23 months of age.

- From these categories, how would you describe your race or ethnic background? (Black or African-American, White, Asian, [other categories])
- On a scale from 1 to 7, would you say you are concerned about the safety of vaccines, where 1 means you are not concerned at all and 7 means you are very concerned?
- On a scale from 1 to 7, would you say you trust vaccination recommendations issued from government agencies, where 1 means you do not trust them at all and 7 means you trust them very much?

Complete recruitment log. Consult recruitment table to determine whether this person is eligible.

<table>
<thead>
<tr>
<th>Racial Background</th>
<th>target n</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>20</td>
</tr>
<tr>
<td>African-American</td>
<td>5</td>
</tr>
<tr>
<td>Asian-American</td>
<td>4</td>
</tr>
<tr>
<td>Other Race</td>
<td>1</td>
</tr>
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</table>

Attitude-related target enrollment

<table>
<thead>
<tr>
<th>concerned about safety</th>
<th>trust vaccine recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>low (1-2)</td>
<td>low/med (1-5)</td>
</tr>
<tr>
<td>med/high (3-7)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>
[if no] I'm sorry, but unfortunately you are not eligible for this study. We are looking for people with a broad array of concerns about vaccination, and we have already spoken with a number of people who feel similarly to you about their concerns and trust about vaccination [or, ]. But thank you very much for talking to me today.

[if yes] Thanks for answering my questions. It looks like you are eligible to participate in this interview, if you would like. It should take about 30 minutes, and we will be tape-recording the interview, but your responses will be kept confidential. You will be paid [compensation amount] dollars for your time. Can I schedule a time that would be convenient for you to do this interview on the phone?

[schedule interview]

Thank you. I will be sending you a consent form that describes the study in detail. I can send it in the mail, or fax it if that would be convenient. You will need to look at that form before we can begin the interview. You will also need to have your oldest child’s vaccine records available during the interview, so please try to locate those before [day of interview].

Recruitment Log for Vaccine Interviews

<table>
<thead>
<tr>
<th>Name, contact info</th>
<th>date</th>
<th>Time</th>
<th>contacted</th>
<th>how many children?</th>
<th>ages &amp; sex</th>
<th>race</th>
<th>concerned</th>
<th>safety</th>
<th>trust govt</th>
<th>age range?</th>
<th>cell over</th>
<th>sampled?</th>
<th>ID #</th>
</tr>
</thead>
<tbody>
<tr>
<td>James Baker, 412-773-9288</td>
<td>7/01/02</td>
<td>6:30pm</td>
<td>yes</td>
<td>2</td>
<td>boy 3 months, girl 21 months</td>
<td>W</td>
<td>2</td>
<td>7</td>
<td>3</td>
<td>y</td>
<td>n/a</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Mary Ellsworth, 310-294-3425</td>
<td>7/01/02</td>
<td>6:45PM</td>
<td>yes</td>
<td>1</td>
<td>girl 19 months</td>
<td>B</td>
<td>3</td>
<td>6</td>
<td>3</td>
<td>n</td>
<td>1</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>
Interview Protocol

Before calling, check to see which stories you will be reading. Take those pages and keep them handy, in the correct order, so that you are not fumbling for them when you get to that point. Use the table below to identify which stories for each interview. Each interviewee will hear 2 stories, in the order noted. Read through both quickly, to remind yourself of their content.

<table>
<thead>
<tr>
<th></th>
<th>Interviewer 1</th>
<th>Interviewer 2</th>
<th>Interviewer 3</th>
<th>Remaining</th>
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</thead>
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<td>8 &amp; 7</td>
<td>7 &amp; 8</td>
<td>6 &amp; 5</td>
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<tr>
<td>2nd</td>
<td>2 &amp; 1</td>
<td>3 &amp; 4</td>
<td>8 &amp; 7</td>
<td>3 &amp; 4</td>
</tr>
<tr>
<td>3rd</td>
<td>4 &amp; 3</td>
<td>1 &amp; 2</td>
<td>2 &amp; 1</td>
<td>8 &amp; 7</td>
</tr>
<tr>
<td>4th</td>
<td>7 &amp; 8</td>
<td>6 &amp; 5</td>
<td>1 &amp; 2</td>
<td>1 &amp; 2</td>
</tr>
<tr>
<td>5th</td>
<td>8 &amp; 7</td>
<td>5 &amp; 6</td>
<td>5 &amp; 6</td>
<td>2 &amp; 1</td>
</tr>
<tr>
<td>6th</td>
<td>3 &amp; 4</td>
<td>4 &amp; 3</td>
<td>4 &amp; 3</td>
<td>7 &amp; 8</td>
</tr>
<tr>
<td>7th</td>
<td>6 &amp; 5</td>
<td>7 &amp; 8</td>
<td>6 &amp; 5</td>
<td>4 &amp; 3</td>
</tr>
<tr>
<td>8th</td>
<td>1 &amp; 2</td>
<td>2 &amp; 1</td>
<td>3 &amp; 4</td>
<td>5 &amp; 6</td>
</tr>
</tbody>
</table>

Before calling, write the subject number and date on the tape label. Be sure tape recorder is functioning. Say aloud the subject number and the two communications that will be read, then pause or stop the tape until the interviewee agrees to start the tape.

Hi, this is [your name here], with Oak Ridge Associated Universities calling to keep our interview appointment. [Oak Ridge: add text for opening]

Our discussion should take about 30 minutes. I have some questions to guide us but please feel free to raise whatever thoughts come to mind as we go along. There are no right or wrong answers, and all the comments that we get will add value to our research. For some questions, I will ask you to answer with a number from 1 to 7, to show how strongly you agree.
Before we begin, may I ask whether you have your child’s vaccine records available? There are just a few questions about your child’s vaccination history. [allow parent to go get records]

I’d like to remind you that I’ll be tape recording our conversation, so that I can type up notes that will accurately capture your thoughts. But I want to reassure you that what you say, along with the recording, will be kept confidential, to the extent allowed by law, to Carnegie Mellon University and Oak Ridge Associated Universities. As indicated on the consent form, the Centers for Disease Control and Prevention, otherwise referred to as the CDC, will receive a report of the findings, but we will not tell them who was interviewed. The CDC fully supports this confidentiality. They want to know what people really think about vaccination.

I'm going to start the tape recorder now, OK?

[turn on tape recorder]

We are now recording this interview.

We will start very generally, just talking about the purpose of vaccines.

1. Can you tell me, to the best of your knowledge, how vaccines are supposed to work in the body to prevent a disease?
   - can you tell me anything about what happens once many people get vaccinated for a disease?[prompt: do you think that would make any difference in preventing the disease?]

2. Now I'd like to turn to your own decisions. Can I have the first name or first initial of your oldest child, so I can refer to that child during the interview? **Note for later questions**
   [if they give an initial or an ambiguous name]
   - is [your first child] male or female?
   - how old is [your first child]?
   - how many other children do you have, and what are their ages?
3. I'm going to ask you to think back to when [your first child] was born, and about the vaccinations that may have been recommended by your doctor. Did anything stick out in your mind about getting [your first child] vaccinated?
   • anything else?

4. What did you think would be the main benefits of getting [your first child] vaccinated?
   • can you explain a bit about how this is helpful?
   • anything else?

5. Did you think there were any down sides to getting [your first child] vaccinated? (if yes)
   • from 1 to 7, how bad do you think that was, using 1 for not bad at all and 7 for extremely bad?
   • anything else?

6. Did you think there were any risks to getting [your first child] vaccinated? (if not mentioned) what do you think could happen? (if yes)
   • from 1 to 7, how bad do you think that would be if it happened, using 1 for not bad at all and 7 for extremely bad?
   • how likely do you think that would be?
   • can you give a guess at the percent chance that this would happen?
   • anything else?

**Individual Assessment of MMR Vaccine**

7. Has [your first child] received the MMR vaccination?  
   [ask the parent to refer to the vaccination records if necessary] (if yes)
   • how many shots has he/she received?
• can you tell me how old [your first child] was when he/she received each shot?
• how would you describe [your first child]'s experience with the vaccine?
[prompt: did he/she have any side effects?]

8. How important is it to you personally that [your first child] was vaccinated against Measles, Mumps and Rubella?
• what in particular makes MMR vaccination important (or unimportant) to you?

9. Did you get [your first child] all the other shots that your doctor recommended up to now?
(if no)
• why not

Now I'm going to read a little background information about the MMR vaccine that we will talk more about.

The Centers for Disease Control and Prevention, also known as the CDC, recommends getting two doses of the MMR vaccine, which protects against Measles, Mumps and Rubella. The first shot is recommended at 12 to 15 months of age and the second at 4 to 6 years of age. All states in the US require schools and day cares to ask for proof that children have been vaccinated, unless the child has a medical, religious or other exemption from getting the vaccination.

10. So first, in general, what are your thoughts about this vaccination policy?
• are there parts of this policy that you think are particularly good or useful?
• are there parts of this policy that you think are problematic?

11. Where did you first learn that your child was supposed to get these shots?**Note for later questions
• from 1 to 7, how well did [this person/source] explain the vaccination, using1 for not well at all and 7 for extremely well?
11. Is there anything else you would have liked [this person/source] to have told you?

[If the response to Question 11 is their doctor or health care professional, Skip 12]

12. Did you try to ask your doctor or other health care professional any questions about the MMR vaccine?
   (if yes)
   • who did you ask?
   • from 1 to 7, did you get satisfactory answers to your questions, using 1 for not at all satisfactory and 7 for completely satisfactory?
   • from 1 to 7, how much did you trust the answers you got, using 1 for didn't trust at all and 7 for trusted completely?
   • is there anyone else you would have liked to answer your questions? who?

13. Did you look at any CDC information about vaccines, such as the one-page vaccine information statements that your doctor may have given you, or the CDC website?
   (If they ask for the website, the address is: http://www.cdc.gov/nip)
   (if yes)
   • how well would you say this information explained the vaccine?
   • from 1 to 7, how helpful did you find it, using 1 for not at all helpful and 7 for extremely helpful?
   • did you get enough information about the vaccine's benefits?
   • did you get enough information about the vaccine's risks?
   • was there anything you were looking for that you couldn't find? what?
   • from 1 to 7, would you say the information was sufficient, using 1 for not sufficient at all and 7 for completely sufficient?
14. Did you seek out any information on your own about any vaccine, or the diseases it would prevent, beyond what you learned from your doctor or the CDC? (if yes)
   - where did you go for more information?
   - from 1 to 7, how helpful was this information, using 1 for not helpful at all and 7 for extremely helpful?
   - did you look for this information before or after your child was due for the vaccination?

15. If you wanted more information about vaccines, where would you go? **Note for later questions**
   - why would you choose [these sources] for information?
   - how much would you trust [these sources]?
   (if they didn’t mention internet as their source)
   - would you use the world wide web to look for information?
   (if yes, or if original source was the internet)
   - how would you find what you wanted on the web?
   - if you used a search engine, such as yahoo or google, what words would you search for?

16. How do you feel about letting parents choose whether to get the MMR vaccination for their children, as opposed to being required by the state?
   - are your feelings about this any different for your own children versus other children?

17. Have you read or heard of any issues about MMR vaccine? (if yes)
   - what have you heard about it?
   - where did you first hear about these issues?
• from 1 to 7, how much would you trust [these sources], using 1 for not at all and 7 for completely?

• from 1 to 7, how important are these issues to you, using 1 for not at all important and 7 for extremely important?

18. Are you confident that the MMR vaccine would protect your child if he/she is exposed to measles, mumps or rubella?
   • can you explain why?
   • from 1 to 7, how confident are you that the MMR vaccine will protect your child, using 1 for not at all confident and 7 for completely confident?

19. Were you ever more or less confident about the MMR vaccine in the past?
   (if yes)
   • why did your confidence change?
   • is there anything that would [further] increase your confidence in the MMR vaccine now?
   • is there anything that would [further] reduce your confidence in the MMR vaccine now?

20. Have you heard of any children experiencing side effects from the MMR vaccine?
   • how did you hear about these stories?
   • what side effects did they experience?
   • from 1 to 7, did you think these side effects were definitely caused by the vaccine, using 1 for definitely not caused by the vaccine and 7 for definitely caused by the vaccine?
   • do you think these stories affected any parents' decisions to vaccinate their children?
   • did these stories have any effect on your decision to vaccinate [your first child] or any children in the future?
21. Do you think that certain children are more likely than others to experience side effects? (if yes)
   - do you think a doctor could tell in advance who these children were?
   - how could they tell?

22. Have you read or heard that some parents are choosing not to give their children the MMR vaccine? (if yes)
   - can you tell me what you've heard?
   - where did you hear about that?

23. What do you think about these parents' decision not to vaccinate their children?
   - from 1 to 7, do you think their decision helps or hurts their children in any way, using 1 for extremely hurtful and 7 for extremely helpful?
   - from 1 to 7, do you think their decision helps or hurts other children in any way, using 1 for extremely hurtful and 7 for extremely helpful

24. Did you have any questions about the vaccines that we didn't talk about, that I can pass along to the researchers on this project? (Explain that you can't answer their questions right now, but that we will be passing them on to those who manage the program)

Sample Communications

Now I'm going to read a couple of short statements that are similar to things you might find on the web. I can't tell you sources of these statements until after the interview, so for now just think of them as things you might find on the web, and you don't really know much about who put them there. What I'd like to hear from you is how convincing you think their arguments are, and why.

Here's the first communication. [read first communication]
OK, that’s the end of the communication, now I’m going to ask you a few questions about it.

25. If a parent was struggling with whether to vaccinate their child, do you think this communication would affect their decision in any way?
   (if yes)
   ● how so? (how would it affect their decision?)
   ● what about this communication do you think would make it most convincing to parents?
   ● is there anything about the facts that makes it especially convincing?
   ● is there anything about the logic or reasoning of the arguments that makes it especially convincing?
   (if no)
   ● why not?
   ● what about this communication do you think makes it not so convincing?
   ● what would make it more convincing?
   ● is there anything about the facts that makes it not very convincing?
   ● is there anything about the logic or reasoning of the arguments that makes it not very convincing?

26. Do you think this communication would affect your own decision differently from how it might affect another parent’s decision?
   (if yes)
   ● how would it be different for your decision?

27. How trustworthy do you think this communication sounds to you? (if asked about the source: Imagine that you just found it on the web, and you don't know what the source is.)
   ● is there anything in what I read that makes you more likely to trust this information?
• is there anything in what I read that makes you not so likely to trust this information?

28. Is there anything else that strikes you about this communication, that we haven't talked about?

OK, Now I’m going to read you a second communication.

Read second of the assigned communications.

Now I’m going to ask the same questions as before, but this time for the communication I just read.

Repeat questions 25-28 for second story.

Thanks. I just have a few more questions, but first let me tell you a little about these communications. The story about Annette/Catherine is based on reports found on the web, but was exaggerated for this communication, and it is not clear that these effects truly were the result of the vaccine or disease. After the interview, if you’d like I can tell you more about where those two communications came from, and give you some more reliable information about the MMR vaccine.

Demographics

Before we close, I have a few questions about your background…

• What is your marital status? [prompt: are you single, married, divorced, separated, or widowed]
• How old are you?
• This may seem silly to ask, but I have to get a response on record. Can you please state whether you are male or female?
• Are you of Hispanic ethnicity?
● Of these categories, how would you define your racial background: Black or African American, White, Asian, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander. You may choose more than one.

Closing Thoughts

● Finally, were there any other thoughts that came to mind while we were talking that you would like to be sure we include in our report?
● If you could offer the CDC one piece of advice about its recommendations for the MMR vaccine, or for anything else, what would that advice be?

Thank you very much for your time. Your comments will be very helpful to our research. If you have any questions about vaccines or about this project, I can put you in touch with the researchers who will do their best to answer any questions you have [if yes: Here is the phone number for Dr. Julie Downs, the principal investigator on this project. 412-268-1862]. Would you like me to read you the scientific information we have on the MMR vaccine?

[If they want to know sources of stories, read below]

The stories or statistics from the anti-vaccine communication came from web pages advocating against vaccination. The statistics are misrepresentations, and in some cases actually fabricated. The link between the MMR vaccine and such disorders as autism has been extensively studied, and even with many very large, very well done studies, no evidence has been found that MMR vaccine causes autism at any level.
The most reliable scientific statistics available indicate that measles, mumps and rubella were at one time devastating diseases in this country, with hundreds of deaths every year in the US as recently as the 1960s. Since introducing the vaccine, the number of cases of measles has dropped to a very low number in this country, although there are still cases overseas, especially where vaccination levels are not high. About 17% of kids have mild reactions to the shot, such as a sore arm, and about 0.03% can have a severe fever or seizures, which cause no damage but can be very frightening for the parents. Nearly all serious side-effects can be avoided by identifying kids who are likely to have a reaction, such as those who have certain allergies or who had mild reactions to vaccines in the past, and by being aware of early signs of side-effects, such as high fever.
Story 1.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. Several million cases of measles and 450 measles-related deaths were reported annually in the United States during the 10 years before the vaccine was available. Since then, the number of cases has dropped to about 100 per year. In the last U.S. measles epidemic, in 1989-90, about 90% of those who died had not been vaccinated. In countries where the MMR vaccine is not available, about a million children still die every year from measles. One in six children experience mild side-effects from the shot, such as a sore arm, and about 1 in 3000 experience more serious side-effects, such as a brief seizure that causes no damage. Measles can lead to brain damage and death. The MMR vaccine gives children antibodies to protect them from these diseases. If most people are vaccinated, then fewer people can expose your children to diseases, which lowers the chance that they will get them. In this way vaccines control formerly common diseases. Like any medicine, vaccines can cause reactions in some people. But nearly all serious complications can be avoided by identifying those likely to have a problem, or who had minor reactions to MMR in the past, and not vaccinating those few individuals. Major reactions after vaccination can be avoided by noticing and treating early signs. Then the risk of the vaccine is extremely low, whereas the benefit remains very high.
Story 2.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. Here is a story about one child’s experience with MMR. Annette had been a bright, healthy baby and had started walking at 13 months. Her mother, following a vaccination schedule, took Annette to get the MMR vaccine at 15 months of age. Nine days after Annette’s shot, she had a low grade fever and became very irritable. Then Annette lost all control of her legs. Now eight-year-old Annette cannot sit without support or walk without braces and a walker. Most of the time she sits in her wheelchair. The U.S. Court of Claims officially acknowledged that Annette suffered post-vaccination encephalopathy following her MMR vaccination as a toddler. There is little research about long-term consequences of vaccination. A group looking at the research has not been able to find any properly conducted trials monitoring the safety of vaccines for more than a few weeks. An Institute of Medicine committee encountered many gaps and limitations in knowledge bearing on the safety of vaccines. The MMR vaccine has been linked to problems including encephalitis, epilepsy, autism, loss of speech, arthritis, diabetes, profound deafness, and paralysis. The development of these conditions, especially autism, is closely linked in time to getting the vaccine. The system continues to fail our children as nothing is done about these problems. The government needs to listen to those who have experienced directly the problems of vaccine safety.
Story 3.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. In the past decade, the number of cases of measles has dropped very low, to about 100 cases per year, and no deaths in recent years. In a recent measles outbreak that was studied by the CDC, over 80% of those involved were fully immunized, and yet they contracted measles. However, many children experience serious complications from the vaccine. The risk of a seizure has been estimated at anywhere from 1 in 2000 to 1 in 130. The risk of brain damage from the vaccine has been estimated at 1 in 6500, while the risk of dying from any of the diseases is a mere one in several million. There is little research about long-term consequences of vaccination. A group looking at the research has not been able to find any properly conducted trials monitoring the safety of vaccines for more than a few weeks. An Institute of Medicine committee encountered many gaps and limitations in knowledge bearing on the safety of vaccines. The MMR vaccine has been linked to problems including encephalitis, epilepsy, autism, loss of speech, arthritis, diabetes, profound deafness, and paralysis. The development of these conditions, especially autism, is closely linked in time to getting the vaccine. The system continues to fail our children as nothing is done about these problems. The government needs to listen to those who have experienced directly the problems of vaccine safety.
Story 4.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. Here is a story about one child’s experience with measles. Susan and Daniel Winter decided not to vaccinate their healthy baby, Catherine, because of stories they had heard about the dangers of vaccination. Days before Catherine's second birthday, she contracted measles, which led to encephalitis and caused permanent brain damage. Catherine is now six, but she doesn’t do things that normal six year olds can do. Instead, her mother feeds her and changes her diaper, and spends the rest of the day helping Catherine interact with a world she will never understand. Every day Susan Winter wishes she had gotten Catherine the MMR vaccination when she had the chance. Measles can lead to brain damage and death. The MMR vaccine gives children antibodies to protect them from these diseases. If most people are vaccinated, then fewer people can expose your children to diseases, which lowers the chance that they will get them. In this way vaccines control formerly common diseases. Like any medicine, vaccines can cause reactions in some people. But nearly all serious complications can be avoided by identifying those likely to have a problem, or who had minor reactions to MMR in the past, and not vaccinating those few individuals. Major reactions after vaccination can be avoided by noticing and treating early signs. Then the risk of the vaccine is extremely low, whereas the benefit remains very high.
Story 5.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. Several million cases of measles and 450 measles-related deaths were reported annually in the United States during the 10 years before the vaccine was available. Since then, the number of cases has dropped to about 100 per year. In the last U.S. measles epidemic, in 1989-90, about 90% of those who died had not been vaccinated. In countries where the MMR vaccine is not available, about a million children still die every year from measles. One in six children do experience mild side-effects from the shot, such as a sore arm, and about 1 in 3000 experience more serious side-effects, such as a brief seizure that causes no damage. Measles can lead to pneumonia, seizures, brain damage and death. Mumps can lead to deafness, meningitis, and, rarely, death. Rubella, also known as German Measles, causes rash, mild fever, and arthritis. People who are moderately or severely ill at the time the shot is scheduled should usually wait until they recover before getting the MMR vaccine. People should not get the MMR vaccine if they have ever had a life-threatening allergic reaction to gelatin or to a previous dose of MMR vaccine. Ask your doctor or nurse for more information about the MMR vaccine. They can give you the vaccine package insert or suggest other sources of information. You can get more information from your local or state health department's immunization program.
Story 6.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. Here is a story about one child’s experience with MMR. Annette had been a bright, healthy baby and had started walking at 13 months. Her mother, following a vaccination schedule, took Annette to get the MMR vaccine at 15 months of age. Nine days after Annette’s shot, she had a low grade fever and became very irritable. Then Annette lost all control of her legs. Now eight year old Annette cannot sit without support or walk without braces and a walker. Most of the time she sits in her wheelchair. The U.S. Court of Claims officially acknowledged that Annette suffered post-vaccination encephalopathy following her MMR vaccination as a toddler.

Preservatives in vaccines include carcinogens that we cannot assume are healthy. There is little research about long-term consequences of vaccination, so how can we trust those who claim it is safe? And yet they are denying parents’ right to decide whether to vaccinate their children. We need to be the ones to weigh the risks and benefits. The benefits of the MMR vaccine are questionable. The diseases are not very harmful and have been practically wiped out. However, the risks of the vaccine can be devastating. Autism has been linked to MMR vaccine, with many cases occurring a few weeks after getting the vaccine. The system betrays our children as more reactions are reported and nothing is done about it.
Story 7.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. In the past decade, the number of cases of measles has dropped very low, to about 100 cases per year, and no deaths in recent years. In a recent measles outbreak that was studied by the CDC, over 80% of those involved were fully immunized, and yet they contracted measles. However, many children experience serious complications from the vaccine. The risk of a seizure has been estimated at anywhere from 1 in 2000 to 1 in 130. The risk of brain damage from the vaccine has been estimated at 1 in 6500, while the risk of dying from any of the diseases is a mere one in several million. Preservatives in vaccines include carcinogens that we cannot assume are healthy. There is little research about long-term consequences of vaccination, so how can we trust those who claim it is safe? And yet they are denying parents’ right to decide whether to vaccinate their children. We need to be the ones to weigh the risks and benefits. The benefits of the MMR vaccine are questionable. The diseases are not very harmful and have been practically wiped out. However, the risks of the vaccine can be devastating. Autism has been linked to MMR vaccine, with many cases occurring a few weeks after getting the vaccine. The system betrays our children as more reactions are reported and nothing is done about it.
Story 8.

The MMR vaccine became available in the U.S. in 1971 to prevent Measles, Mumps and Rubella. Here is a story about one child’s experience with measles. Susan and Daniel Winter decided not to vaccinate their healthy baby, Catherine, because of stories they had heard about the dangers of vaccination. Days before Catherine's second birthday, she contracted measles, which led to encephalitis and caused permanent brain damage. Catherine is now six, but she doesn’t do things that normal six year olds can do. Instead, her mother feeds her and changes her diaper, and spends the rest of the day helping Catherine interact with a world she will never understand. Every day Susan Winter wishes she had gotten Catherine the MMR vaccination when she had the chance. Measles can lead to pneumonia, seizures, brain damage and death. Mumps can lead to deafness, meningitis, and, rarely, death. Rubella, also known as German Measles, causes rash, mild fever, and arthritis. People who are moderately or severely ill at the time the shot is scheduled should usually wait until they recover before getting the MMR vaccine. People should not get the MMR vaccine if they have ever had a life-threatening allergic reaction to gelatin or to a previous dose of MMR vaccine. Ask your doctor or nurse for more information about the MMR vaccine. They can give you the vaccine package insert or suggest other sources of information. You can get more information from your local or state health department's immunization program.
Quantitative Data Log for Vaccine Interviews

As the interview is ongoing, the interviewer should indicate the quantitative responses to the red questions. Although these can be written anywhere, they should eventually be entered into the table shown below. A copy should be kept on location, and a second copy will be sent to Carnegie Mellon for data entry and analysis.

The sample log below shows one hypothetical interviewee’s responses, with some suggested abbreviations (e.g., “mo” in place of “months”). A notation of any abbreviations should be kept attached.

<table>
<thead>
<tr>
<th>ID #</th>
<th>date</th>
<th>time</th>
<th>age first child</th>
<th>other kids</th>
<th>down sides</th>
<th>risks</th>
<th>% chance risk</th>
<th>how many MMR shots</th>
<th>shot 1</th>
<th>shot 2</th>
<th>explain vaccination</th>
<th>trust</th>
<th>satisfied doctor</th>
<th>trust doctor</th>
<th>CDC helpful</th>
<th>CDC sufficient</th>
<th>outside info helpful</th>
<th>trust outside info</th>
<th>important issues</th>
<th>confidence in MMR</th>
<th>side effects</th>
<th>decision (own kids)</th>
<th>decision (other kids)</th>
<th>marital status</th>
<th>age</th>
<th>sex</th>
<th>Hispanic</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
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<td>7/7/02</td>
<td>3:30 pm</td>
<td>19 mo</td>
<td>no</td>
<td>2</td>
<td>3</td>
<td>10</td>
<td>13</td>
<td>1 mo</td>
<td>.</td>
<td>1</td>
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<td>.</td>
<td>2</td>
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<td>5</td>
<td>3</td>
<td>6</td>
<td>4</td>
<td>5</td>
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<td>27 F</td>
<td>No</td>
<td>B</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interviewer Hints

Attitude

- Try to forget what your personal opinions are, how you would answer the questions and what you know to be true about the topic.
- Don’t show surprise at what you hear, no matter how ridiculous it may sound.
- Don’t share any of your thoughts during the interview, as this may influence what the respondent tells you. You can chat with them later.
- Accept what they tell you as the TRUTH of the world. Don’t be skeptical of what they say.
- There are no “wrong” answers to our questions. We are just trying to find out what they think.
- Do not correct what they tell you. Also, do not try to “help” them.
- Be friendly, enthusiastic, energetic.
- Try to maintain a casual atmosphere. People will talk much more if they are relaxed.
- People like to talk and be taken seriously. Give them the opportunity.
Don't act hurried. Don't even think about the next question until you have heard everything they have to say on the current one. People will talk more if you show that you have the time.

Don't challenge what they tell you, just try to get them to clarify.

**Mechanics**

- You are here to find out what they have to say. Focus on the person.
- Follow the protocol.
- Take time to ask every question and wait a few seconds after the person stops talking to make sure that they have completed their thoughts.
- Encourage them to tell you everything that comes to mind, even if they tell you that they really don't know.
- Be an active listener. You will not be able to give nonverbal cues on the phone, so use low volume assurances to encourage them to talk.
- Listen to what people say in response to every question. Decide if you need to ask follow-up questions. Anticipate the next step in the research project; Is there anything that could be interpreted ambiguously if you read what they just said on a piece of paper? If so, then ask them to elaborate.
 Ask follow-up questions with the words that the person has used.

 Ask what they mean in the terms that they have first used, even if they are wrong.

 If they have spoken in a very low voice, ask them to please repeat what they have said and ask them to speak up.

 If you have asked for a probability, next ask them why they gave it “___%”, repeating the probability that they have given you. This acts as a check that you have correctly heard what they have said.

 If they ask questions during the interview about the “real” answers, tell them that you can talk about it after the interview.
Instructions to Transcribers

FORMAT

Transcripts should be single spaced, with an empty line separating what the interviewer says with what the participant responds. The final transcription should begin with the interviewer (I), followed by the subject (S), and continue in this format:

I: What do you think about this topic?

S: I know a lot about it. Um, let me start by saying just a little bit. Uh, um, what exactly was I supposed to say about [inaudible – 2 or 3 words] actually?

I: Just whatever you think.

S: Oh, OK. Well, I think [long pause], I think it's really neat.

Only start a new paragraph when the speaker changes between interviewer and subject.

PROCEDURES

We will try to check for bad tapes before handing a tape out for transcribing. That way you won’t waste your time listening to bad tapes. The tapes will vary in quality due to the different locations and sound conditions where the interviews were conducted.

The tapes will be marked with a number. Please put the identifying number on the first line of the document. Using the above format, please transcribe the tapes VERBATIM. This means, include any “ums, yeahs, oks, I don’t knows, etc.” When the subject respond with “uh-huh, uh-hmm” please type their answer and in parentheses a (yes) or (no) to indicate what their answer implies.

We are trying to get a feel for the timing of the interviews from the transcripts alone. If there is a pause on the tape, please indicate it with “[pause] “ or a comma, whichever the length of the pause seems to indicate. Words or phrases that are difficult to hear should be indicated by [inaudible]. If you can’t decipher the inaudible words, please indicate the number of words they say if possible [inaudible - 3 words].
After going through the tape once, please listen to the entire tape again to fill in any inaudibles that may become audible once you have the context of the conversation. Please fill in any words that you may have missed on the first round. One word can completely change the meaning (i.e. you get it vs. you can’t get it).

Save the transcript as a text only file on a disk, with the filename “transcript” and the subject number.
Next Steps

Conducting and transcribing the interviews using the very particular method described above is important because of the fine level of analysis to be done. The content of the interviews will be coded in terms of the expert model presented in figure 7 above. Each interview will be broken down to the level of sentences, and formatted in a coding worksheet. Two coders will independently judge every sentence, and classify the concepts being communicated in terms of one or more specific links in the expert model. The precise layout allows a strict reliability to be calculated, considering for every sentence whether each code was assigned. Training progresses with early interviews to ensure that reliability between the coders is sufficient to conclude that the interviews are being systematically represented in terms of the model.

Once this coding is complete, it is possible to take any category of people (whether that be all respondents, subdivisions that were part of the selection criteria, or even particular individuals) and represent their “mental model” of the process by drawing a representation of the links from the expert model that were mentioned more often, by noting links that were more associated with particular questions, or even by contrasting links that were more associated with correct versus incorrect statements made by the interviewees. These representations provide a descriptive view of how the
decision space is represented, and can serve as a model for future interventions.

Focusing special attention on gaps in mental models (i.e., links within the expert model that don’t show up in mental models) and on links that are fraught with misunderstandings can help maximize the impact of an intervention, especially when time is limited for the target audience. Below is an example of this process, from a project looking to reduce the social stigma associated with genital herpes.

**Coding of the transcribed interviews**

Starting with the transcribed interviews, the content is formatted into a detailed coding sheet. Below is an excerpt from interview protocol on herpes and stigma, followed by an excerpt from the portion of one interview where these questions were asked.

*Gary had been dating Kim for a long time and they were in love and planning to get married. Kim had genital herpes, and Gary didn’t have it. He still wanted to be with her, but he decided that he just couldn't marry her.*

18. What are your reactions to Gary's decision?

- Would you do the same thing? Why or why not?
- Does Gary’s decision seem like the best decision he could have made? Why or why not?

…

43. Have you ever had to tell anyone about your genital herpes?
• [if yes] Can you tell me how that went?
• [if yes] What was their reaction?

44. Have you noticed any differences between telling a potential long-term partner and a casual partner?

These questions were formulated based on the expert model on the process of exposure, treatment, sexual decision-making and stigma associated with genital herpes, shown below. In this diagram, each node is labeled with a letter or digit. This labeling allows each link to be sensibly represented as a two-character code.

**Expert model from herpes and stigma project**
Coding is attempted in terms of links rather than nodes, where possible. When explaining answers, people naturally talk in terms of links (or relationships) between concepts, so most statements naturally fall into this type of code. Subcodes are included to allow for further analysis of concepts that cut across all codes, such as whether the statement is correct. The table that follows shows a sample excerpt from an interview on this topic. The two-character code appears, accompanied by any relevant subcodes, for each sentence with codable content. In some cases, more than one code appears. There is no limit to the number of codes that can be assigned to any given sentence.

**Interview coding sheet from herpes and stigma project**
Development of targeted intervention

Finally, these data are analyzed and used as the basis for a targeted intervention. The interviews have served to identify which areas need attention, what underlying knowledge structure is available to build upon, and how the audience thinks about the problem. Previous interventions have been shown to improve knowledge and behavior, and have even shown patterns consistent with improvement in clinical outcomes of
disease acquisition, although we have not conducted studies of sufficient size to evaluate that outcome.

Below are some images from the herpes and stigma intervention described above. The innovative nature of this intervention is a result of the detailed understanding of the decision processes on this topic, which would not have been possible if a less structured, less detailed, less systematic approach was taken in the formative research.