

Attitudes and Concerns of Kansas Parents Related to Childhood Immunization

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The Immunize Kansas Kids project is a unique partnership among the Kansas Department of Health and Environment, the Kansas Health Institute and dozens of stakeholder organizations. The goal is simple: to protect every Kansas child from vaccine-preventable diseases.

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EXECUTIVE SUMMARY

Public health practitioners in the United States frequently cite vaccines against common communicable diseases as one of their greatest achievements. High vaccination rates for childhood diseases such as polio, measles, mumps, rubella, and chickenpox have brought about dramatic declines in disease incidence rates. Despite this success, in recent years increasing numbers of parents have begun to question vaccine safety, effectiveness and necessity. Growing numbers of parents are expressing concerns and choosing to either delay or refuse one or more vaccinations recommended for their children (Omer 2012, Centers for Disease Control (CDC) 2012). These trends raise concern among public health practitioners. Sustaining high rates of vaccination coverage among children is vital to the prevention of outbreaks of communicable disease.

Understanding the driving forces behind parents' vaccination concerns or decisions to forgo vaccinations for their children is essential for the development of effective strategies and approaches for effectively addressing those concerns and maintaining high vaccination coverage rates. Although a number of published studies have examined the underlying reasons for parental vaccine concerns either nationally or in other states, current Kansas-specific data and analyses have not been available. This study was designed to address that knowledge gap. The objective of this study was to develop a more complete understanding of Kansas-specific trends, patterns and reasons for parental concerns about childhood immunization, and to explore potential opportunities for more effectively addressing the vaccine-related questions and concerns of Kansas parents.

This study utilized a mix of literature review, secondary analyses of existing data sources and reports, and primary qualitative data collection. Methods and specific findings are described in detail in the body of this report. Highlights are summarized in this section.

Across the U.S, a small, but growing percentage of parents are raising concerns and questions about the immunization schedule currently being recommended for their children. Published studies suggest that these parents are predominantly well-educated, higher-income parents who are trying to balance perceived risks against benefits to make the best decisions for

the well-being of their children. Their concerns revolve primarily around issues of vaccine safety, effectiveness and necessity. They are acutely aware that vaccines are not entirely risk-free, and seek information about the level and nature of risks for their children if they accept immunization. They cite instances of disease occurring among vaccinated children, and continuous additions of booster doses to the recommended immunization schedule as reasons for doubting vaccine effectiveness. Vaccine-hesitant parents frequently view the currently recommended immunization schedule (Appendix E) as too much, too soon for a young child's immune system, and question the necessity and wisdom of giving so many immunizations so early in a child's life. Some express the belief that they can more effectively protect their children from disease through extended breastfeeding, sanitation, and isolation techniques than through immunization. Few of these parents are rejecting all immunizations. Many are attempting to evaluate the potential risks, benefits and necessity of each recommended vaccine, and making decisions to accept or reject on a vaccine-by-vaccine basis. Some are requesting alternate schedules of vaccine administration to reduce the number of antigens a child is exposed to at one time, or to delay administration until the child is older and perhaps at higher risk for exposure through contact with other children. In this study, some Kansas parents expressed frustration with what they described as a "one size fits all" approach to childhood immunization, and indicated a desire for an immunization plan that was more customized to the anticipated risks and benefits for each individual child.

Published studies show that when vaccine-hesitant parents seek answers to their questions and concerns, most turn first to their children's physicians. Participants in this study expressed high levels of trust and described positive relationships with their children's doctors, and most felt that they had been able to effectively discuss their concerns. Parents expressed appreciation for open, honest, respectful discussions that acknowledge possible risks of both immunization and choosing not to immunize. They also appreciated that when they had made a decision not to immunize, their child's physician respected that decision. Some participants reported that they had carefully sought out and selected their child's current physician because that provider was open to discussing their questions and concerns, and respected their decisions.

Other sources of information frequently mentioned by parents interviewed in this study included the U.S. Centers for Disease Control and Prevention (CDC) website, the American Academy of Pediatrics website and various books. Internet sources were less often viewed as a key resource. Some study participants indicated that they also seek out and read peer-reviewed journal articles, although obtaining access to the articles was sometimes difficult.

If public health and health care practitioners wish to maintain high immunization coverage rates, they will need to be responsive to the questions and concerns raised by vaccine-hesitant parents. A number of possible options have been suggested in this report. Although discussions with vaccine-hesitant parents take time and add to demands on practitioners' already-busy schedules, they are also an opportunity to strengthen the provider-patient relationship, to encourage patient (parent) personal responsibility and participation in the decision-making process, and to ensure that parents have credible information resources upon which to base their decisions.

INTRODUCTION

Public health practitioners in the United States frequently cite vaccines against common communicable diseases as one of their greatest achievements. High vaccination rates for childhood diseases such as polio, measles, mumps, rubella, and chickenpox have brought about dramatic declines in disease incidence rates. Despite this success, in recent years increasing numbers of parents have begun to question vaccine safety, effectiveness and necessity. Some parents are expressing concerns and choosing to either delay or refuse one or more vaccinations recommended for their children (Omer 2012, Centers for Disease Control (CDC) 2012), potentially placing their own children and others at risk for disease through reduced immunization coverage rates and reduced effectiveness of “herd immunity” protection. While most public school systems require that children be fully immunized at entry into kindergarten, all states allow exemptions from this requirement for medical reasons, and all but two states in the U.S. currently allow exemptions for religious reasons. A smaller number (19 in December 2012) of states allow parents to claim exemptions for their child based upon personal beliefs (NCSL 2012). In recent years, rates of immunization exemption claims have been on the rise, particularly in states where personal belief exemptions are allowed (Omer 2008).

These trends raise concern among public health practitioners. Sustaining high rates of vaccination coverage among children is vital to the prevention of outbreaks of communicable disease. A number of published studies have found significant relationships between geographic areas where vaccine exemption rates are higher and incidence of potentially serious vaccine-preventable diseases such as pertussis and measles (Omer 2009, Sugerman 2010).

Understanding the driving forces behind parents’ vaccination concerns or decisions to forgo vaccinations for their children is essential for the development of effective strategies and approaches for addressing those concerns and maintaining high vaccination coverage rates. Although a number of published studies have examined the underlying reasons for parental vaccine concerns either nationally or in other states, current Kansas-specific data and analyses have not been available. This study, conducted at the request of the Immunize Kansas Kids coalition, was designed to address that knowledge gap through a combination of literature review, analyses of existing data sources, and qualitative data collection through a small number

of focus groups and interviews with parents of young children in Kansas. The objective of this study was to develop a more complete understanding of Kansas-specific trends, patterns and reasons for parental concerns about childhood immunization, and to explore potential opportunities for more effectively addressing parents' vaccine-related questions and concerns.

METHODS

This study utilized a mix of literature review, secondary analyses of existing data sources and reports, and primary qualitative data collection. Data sources and methods are summarized below:

1. Literature Review - A search and review of peer-reviewed medical literature was conducted to provide background understanding of national trends and research findings related to vaccine hesitancy. Searches were conducted using the National Library of Medicine PubMed database, and search terms such as "vaccine hesitant," "parental concern," "exemption," combined with "immunization." Abstracts of the resulting articles were reviewed for relevance to the objective of this study, and full text of relevant articles were obtained and reviewed. Citations included in those studies were reviewed to identify additional relevant sources.
2. Kansas Kindergarten Immunization Coverage Survey - Results and findings from the Kindergarten Immunization Coverage Survey conducted annually by the Kansas Department of Health and Environment (KDHE) were reviewed and analyzed to identify trends and geographic regions within Kansas where immunization exemption rates are highest or have been rapidly increasing. A sample of individual exemption records gathered by KDHE as part of the 2012 Kindergarten Immunization survey was reviewed by KHI staff.
3. Kansas Behavioral Risk Factor Surveillance Survey - In 2012, the Kansas Behavioral Risk Factor Surveillance System (BRFSS) survey included a state-added module of questions asking about parents' confidence in and concerns about childhood vaccines. Summary results from this survey were reviewed and are included in this report.
4. Qualitative Data Collection - Information available from existing sources was supplemented by focus groups and individual structured interviews with parents of young children in Kansas who identified themselves as having questions or concerns about the immunizations being recommended for their children. The purpose of these groups was to explore in more depth the immunization questions and concerns that parents have, and the sources of information that they rely upon to answer their questions or guide their immunization decisions.

Focus Groups and Interviews

The target population for inclusion in the focus group discussions was parents of children ages one to six years that had questions or concerns about childhood immunization recommendations but were not adamantly anti-immunization. Target communities for focus groups were identified through review of school district-level rates of kindergarten immunization exemptions derived from the most recent Kansas Kindergarten Immunization Coverage Survey (conducted by KDHE), and through input from local health department and school health representatives. A convenience sample of three communities was selected based upon higher rates of immunization exemption from immunization survey data, input from health department staff, and community demographic profiles that suggested an increased likelihood of vaccine hesitancy among community residents. The selected communities were 1) Lawrence/ Douglas County, 2) Topeka/ Shawnee County and 3) Hutchinson/ Reno County/ Kingman County. Focus group participants were recruited by posting invitation flyers at public locations where parents of young children were likely to frequent in the target communities and by distributing study invitations to parents of children enrolled in daycare, preschool, or alternative school programs in the communities.

Appropriate community locations for posters were identified in collaboration with representatives of the local health departments in each community. Interested parents were invited to call the Kansas Health Institute (KHI) for additional information about the study, and callers were then asked a series of three screening questions designed to identify parents who 1) had at least one child between the ages of one and six years, 2) made health care decisions for that child, and 3) had ever questioned whether they should allow that child to receive a recommended vaccination. Parents who answered all three questions affirmatively were considered eligible and were invited to participate in the focus group/interview process.

While the original study plan was to conduct all qualitative data collection through small focus groups, scheduling challenges precluded that option. One in-person focus group was conducted, and the remaining individuals who had expressed interest in participating in the study were offered the option of individual interviews conducted by telephone. After completing an informed consent process, participants were asked to complete a brief questionnaire (Appendix

C) designed for the purpose of producing summary demographic and attitudinal descriptions about the participant group. Interviews were then conducted using a pre-defined set of key questions and follow-up probes (Appendix D). Focus group discussions and interviews were facilitated by members of the study team who had received training on the study protocols and qualitative data collection process. All questions to parents were asked in a neutral, nonjudgmental tone. Facilitators were careful not to agree or disagree with any of the viewpoints shared by participants, but did occasionally ask probing follow-up questions for the purpose of clarification.

The study team emphasized to participants that there would be no attempt made to change participant opinions about immunization, and that all responses shared by participants would be considered confidential. Participants received a \$25 gift card offered in appreciation of their time and participation.

In total, 17 individuals responded to the study invitation; all of those met the screening criteria and were determined eligible for participation. One focus group was conducted with seven participants, and individual interviews were conducted with five additional subjects.

Human Subjects Approval

This study was reviewed and approved by the Institutional Review Board of KDHE, Study # 2013-1-A.

PARENTAL ATTITUDES AND CONCERNS: U.S. PERSPECTIVE

Findings from Published Studies

Reports from numerous studies of parental vaccine hesitancy and rates of immunization exemption claims in the United States have been published in the peer-reviewed literature. Although few of them are specific to Kansas, they offer useful insights that may be applicable to the state. For this reason, key findings are summarized and included in this report.

Prevalence of Vaccine Hesitancy

Numerous studies have documented an erosion of parental confidence in childhood vaccines. A national survey of parents conducted in 2000 found that 19 percent of parents had “concerns about vaccines.” In a subsequent similar survey, conducted in 2009, the proportion of parents with concerns had increased to 50 percent (Gowda 2013). Twenty-eight percent of parents responding to the 2003-2004 National Immunization Survey conducted by the CDC reported that they had either permitted their child to be immunized although they were not sure it was the best thing to do, decided to delay an immunization, or refused to allow an immunization recommended for their child (Gust 2008). Results from the 2010 HealthStyles survey found that a substantial majority (76 percent) of parents of children age six or younger had one or more questions or concerns related to immunizing their children (Kennedy 2011a).

Vaccine hesitancy does not mean that parents will not allow their children to be immunized. The majority of vaccine-hesitant parents are seeking additional information and reassurance prior to making a decision about immunizing their child. Once parental questions have been sufficiently addressed, many parents will permit their child to be immunized. Some parents may delay immunizations or request alternative immunization schedules for the purpose of reducing the number of shots received at a single clinic visit. Others may selectively immunize, accepting the vaccinations that they perceive to be most important, but refusing those that are felt to be unnecessary, ineffective or potentially associated with increased risk of adverse reactions. A small number (one to two percent) refuse all recommended vaccines (Gowda 2013). Delay or refusal of one or more specific vaccines is more common. In a national study that found 28 percent of parents to be vaccine hesitant, approximately two-thirds of those parents delayed or refused specific vaccines (Gust 2005). Another national study conducted in 2009 found that 11.5 percent of parents had refused at least one vaccine for their child, with varicella and Human papillomavirus (HPV) most being frequently refused (Freed 2010). In a 2009 national survey of pediatricians and family medicine physicians, eight percent of physicians reported that more than 10 percent of parents in their practices had refused at least one vaccine recommended for their child, and 20 percent of physicians reported that more than 10 percent of parents requested alternative scheduling of vaccine administration. In the same study, 53 percent of physicians reported spending 10-19 minutes when talking with parents with substantial concerns about

immunization, and eight percent reported spending 20 or more minutes in discussion (Kempe 2011).

Characteristics of Vaccine-Hesitant Parents

A number of studies have examined characteristics of vaccine hesitant parents and vaccine refusers, with mixed findings. Analyses of data collected in the National Immunization Survey between 1995 and 2001 revealed that parents of unvaccinated infants were more likely to be married, older (30 years or older), college educated, with higher incomes (annual household incomes equal to or greater than \$75,000) compared to parents of vaccinated infants (Smith 2004). Gust (2008) found that parents with higher educational levels and higher household incomes were more likely to question or have concerns about immunization recommendations. Salmon *et al.* (2005) found that parents claiming immunization exemptions for their children were older and had higher levels of education than parents of vaccinated children, although the two groups were similar in terms of household income levels and race. In contrast to these results, another study by Gust and colleagues (2005), found that parents with lower levels of education (less than 12 years) and parents with smaller household size (two or three members in the household) were more likely to say that they lacked access to enough information about immunization than their counterpart parent groups in the study. In their review of trends in parental vaccine hesitancy, Gowda and Dempsey (2013) cite several studies reporting that parents with less formal education have greater distrust in the medical community, express more concerns about vaccine safety, and have less belief in the necessity and efficacy of vaccines.

Smith *et al.* (2011) used data from the 2009 National Immunization Survey to examine relationships between parental psychosocial factors and immunization status of their children aged 24 to 36 months. Compared to parents whose children were fully immunized, parents who delayed or refused vaccines were less likely to believe that vaccines are necessary to protect the health of children, that their child might contract a disease if unvaccinated, and that vaccines are safe. Salmon *et al.* (2005) found that parents of vaccine-exempt children were significantly more likely than parents of vaccinated children to report low perceived vaccine safety and efficacy, low levels of trust in government, and lower perceptions of susceptibility to and severity of vaccine-preventable diseases. In the same study, parents of exempt children reported lower levels

of confidence in medical, public health and government sources, and were more likely to report confidence in alternative medicine professionals than parents of vaccinated children.

Reasons for Vaccine Hesitancy

Published studies cite a wide range of factors that contribute to parental concerns about current childhood immunization recommendations. Factors most frequently mentioned are summarized here (in no particular order):

- Pain and discomfort experienced by the child - Although this issue may sometimes be discounted by health care practitioners as trivial, many parents of young children face immunizations with apprehension and dread of the pain and discomfort associated with injection, and the possible fever and discomfort that may be experienced following immunization (Gowda 2013, Kennedy 2011b).
- Reduction of disease prevalence - The enormous success of immunization programs in reducing the prevalence of childhood diseases may also be a contributing factor in parental vaccine hesitancy. As historically important diseases such as polio have been nearly eradicated, awareness of their potential for devastating morbidity and mortality has also faded. Today's parents have little or no experience with vaccine-preventable diseases such as polio, and cannot fully appreciate the benefits of vaccination or the risks of not vaccinating. High overall immunization levels have also resulted in perceptions of diminished need for immunization among some parents, assuming that their children will be protected through herd immunity created by high rates of immunization among other children (Gowda 2013, Gust 2004, Lantos 2010).
- Increasing numbers of vaccines and complexity of schedule - With 24 immunizations recommended between birth and the child's second birthday, and up to five injections recommended for simultaneous administration at some healthcare visits (CDC 2014), some parents have raised concerns about how effectively a child's immune system can handle being presented with so many antigens in a compressed period of time.

- Erosion of public trust - In recent years, numerous concerns have been raised about both the safety of and the need for certain immunizations (Larson 2011). Immunization safety has become a contentious area of public health policy, with discourse around it having become increasingly polarized and exceedingly difficult. The numerous controversies and allegations surrounding immunization safety signify an erosion of public trust in those responsible for vaccine research, development, licensure, scheduling, and policymaking (IOM 2004). Questions about the business and financial motives of the vaccine industry and their perceived influence in public health have also contributed to declining trust levels (Larson 2011).
- Growing public interest in “natural” approaches to maintaining health - A growing public interest in “green” and “natural” lifestyle alternatives has exerted influence on decision-making related to health and health care. Some parents have expressed beliefs that vaccine-induced immunity is inferior to that acquired through the natural course of disease, and therefore a preference that their children be allowed to develop “natural” immunity to diseases perceived as low-risk, such as chicken pox (Gowda 2013, Siddiqui 2013).
- Information access - Perceptions that vaccines pose a safety risk have increased in recent years (Kempe 2011). Stories of post-vaccine complications, although infrequent, have created a heightened awareness of potential adverse outcomes and may result in a misperception of increased risks for some parents (Larson 2011). Misinformation is easily promulgated and readily available, and may be difficult to distinguish from rigorously validated scientific information. Public access to databases which collect reports of possible adverse reactions to vaccines and compensation awarded for vaccine-associated injuries may also elevate parental perceptions of risk associated with immunization.
- Provider-parent communications - A changing culture of physician-patient interaction has been observed in recent years. Increasingly, patients want to be an informed and active partner in decision-making (Gust 2005, Siddiqui 2013). Increasing time constraints faced

by providers may sometimes make it difficult for physicians to adequately address parents' questions and concerns and result in a less satisfactory communication experience for both patient and physician (Siddiqui 2013).

- Safety concerns - Few, if any, health care treatments are without some risk of harm, including childhood immunization. Although the majority of public health and health care practitioners would consider the risks of adverse outcomes to be small in comparison to benefits, serious complications including neurological sequelae and death do infrequently occur. Reports of possible adverse reactions, whether validated or unconfirmed, may be disseminated widely through media outlets, social media and word of mouth, and concerns about safety may adversely affect parents' decisions to immunize their children (Gust 2004). Although it has since been discredited, a widely publicized scientific study purporting a linkage between the MMR vaccine and autism planted seeds of doubt of vaccine safety in the minds of many, and continues to exert influence on some parents (Wakefield 1999, Larson 2011). Safety concerns reported by Luthy (2010) in a study of Utah parents included autism, immune system overload and other adverse reactions. In that study, concerns related to immunization safety and a lack of perceived necessity for immunization were most frequently cited by parents as reasons for vaccine-hesitancy. In a 2009 survey of more than 2,500 parents of children aged 0 to 17 years, more than half (54 percent) of responding parents expressed concerns regarding serious adverse effects of vaccines (Freed 2010).
- Religious or ethical objections - Religious beliefs or ethical objections are raised less frequently by parents, but do account for some parental decisions to refuse some or all vaccines. Vaccines that have been derived using fetal cell tissue or bovine tissues are often mentioned as a reason for refusal (Domachowski 2013).
- Opposition to mandates - Some parents object to mandatory immunization of their children on the basis that it should be the parent's right to make decisions in the best interest of their children, and that government should not intervene in the decision-making process.

In the 2010 HealthStyles survey, 77 percent of parents of children age six or younger reported having one or more questions or concerns related to immunizing their children. Concerns about pain associated with immunization, and the number of vaccines being recommended topped the list of concerns (Table 1).

Table 1. Vaccine Concerns Reported by Parents of Children Age 0 to 6 Years, 2010

Concern	Parents reporting concern (%) n=376
It is painful for children to receive so many shots during one doctor's visit	38%
My child is getting too many vaccines in one doctor's visit	36%
My child is getting too many vaccines during the first two years of life	34%
Vaccines may cause a fever in my child	32%
Vaccines may cause learning disabilities, such as autism	30%
The ingredients in vaccines are unsafe	26%
Vaccines are not tested enough for safety	17%
Vaccines may cause chronic disease	16%
Vaccines are given to children to prevent diseases they are not likely to get	11%
My child will not be vaccinated on time because there are not enough of some vaccines	9%
Vaccines are given to children to prevent diseases that are not serious	8%
No concerns	23%

Source: Kennedy *et al.* Confidence about Vaccines in the United States: Understanding Parents' Perceptions. Health Affairs, 2011; 30(6):1151-59.

Information Sources Valued by Vaccine-Hesitant Parents

Parents who have questions or concerns about the immunizations recommended for their children frequently seek out additional information before deciding whether or not to allow the child to be vaccinated. Information may be gathered from a variety of sources, including child's health care provider, family, friends, peers and the media. Using data from the 2009 HealthStyles survey, Kennedy (2011b) found that parents relied most heavily on other people, particularly health care providers, as information sources. Eighty-five percent of responding parents identified health care professionals as among their top three most important sources of

immunization information (Table 2). Just over half of parents “strongly agreed” that they trusted the vaccine advice offered by their child’s health care provider, and another 31 percent “somewhat agreed” (Kennedy, 2011a). Findings from another survey conducted in 2009 were similar; with the child’s doctor identified most often as a trusted source of information, followed by other health care providers and government vaccine experts (Freed 2011). This study provided additional perspective, reporting that 26 percent of parents placed at least some trust regarding vaccine-safety information with celebrities, and 73 percent placed at least some trust in the reports of other parents who believed that their child had been harmed by a vaccine.

Table 2. Top Three Most Important Sources of Immunization Information for Parents, 2009

Information Source	Parents Citing Source as Among Top Three in Importance (%)
Health care professionals	85
Family members	46
American Academy of Pediatrics	28
CDC	26
Internet	24
Friends	22
Newspapers	5
Magazines and television shows	4
Radio	1

Source: Kennedy, Basket, & Sheedy. Vaccine Attitudes, Concerns and Information Sources Reported by Parents of Young Children: Results from the 2009 HealthStyles Survey. *Pediatrics*, 2011; 127(S1):S92-99.

Although health care professionals are consistently identified by parents as their most important source of immunization information, the influence of family and friends is also powerful. A study of parents in King County, Washington examined the influence of social networks on parents’ vaccine decisions, and concluded that the variable most predictive of parental vaccination decisions was the percent of parents’ people networks recommending nonconformity (Brunson 2013).

In our current information-rich environment, it can sometimes be difficult for parents to assess the reliability of the information with which they are presented. Agenda-driven groups or individuals can easily create convincing websites filled with misleading or erroneous

information, and parents seeking answers may have difficulty determining which claims should be believed. One study discussed the challenges that parents are often confronted with as they attempt to distinguish reliable health information from misinformation, particularly when looking for information on the Internet (Pineda 2011). The authors suggest that providers should be prepared to offer guidance and resources to help parents evaluate information and locate reliable sources. They offer specific suggestions, such as encouraging parents to begin their research with a known, trustworthy website rather than a search engine, and a list of criteria to apply in evaluating a health website. Websites for the National Network for Immunization Information (NNII), CDC, the World Health Organization, and the Vaccine Education Center at the Children's Hospital of Philadelphia are recommended as parent-friendly resources providing reliable information.

Immunization Exemptions

State-level school immunization requirements have played a significant role in achieving and maintaining high immunization rates in the United States. All states and the District of Columbia require that children entering school provide evidence that they have met the state's vaccination requirements (Omer 2006). There are, however, exceptions to these requirements. All states allow exemptions to immunization requirements for medical reasons. Some states also allow immunization exemptions based upon religious or philosophical beliefs of parents. As of December 2012, all states except Mississippi and West Virginia allowed religious exemptions, and nineteen states allowed philosophical or personal belief exemptions (NCSL 2012). States also vary in the ease with which parents are allowed to claim non-medical exemptions, and greater increases in exemption rates have been observed in states where it is relatively less difficult for parents to claim an exemption (Omer 2006). Higher rates of immunization exemption claims have been associated with outbreaks of vaccine-preventable diseases, particularly pertussis and measles (Omer 2006, Omer 2008, Sugerman 2010).

Increases in rates of non-medical immunization exemption have paralleled rising rates of parental vaccine-hesitancy and immunization concerns, and have risen faster in states that offer personal belief exemptions than in those that do not (Omer 2006, Omer 2012). During the 2011-2012 school year, state rates of total immunization exemption claims ranged between 0 and 7.0

percent of children enrolled in kindergarten, with a median rate of 1.5 percent. The vast majority (approximately 80 percent) of the exemption claims were non-medical (CDC 2012).

Strategies for Addressing Vaccine-Hesitancy

Although parents may seek immunization information from many sources, the influence of physicians remains strong and evidence suggests that physicians are a primary resource in addressing concerns and reducing vaccine hesitancy among parents of young children (Gowda 2013, Gust 2005, Smith 2006, Healy 2011). Smith (2006) identified physicians as the source of information most frequently consulted by parents with vaccine-related concerns, and found a strong association between the influence that health care providers have on parents' decisions to vaccinate their children and vaccination coverage rates. Another study found that the largest proportion of parents who changed their minds about delaying or refusing a vaccination for their child listed "information or assurances from health care provider" as the main reason (Gust 2008).

Parents want open, honest, respectful communication with their health care provider. Trust is essential to effective patient-provider communication. Healy (2011) concluded that to effectively communicate with vaccine-hesitant parents, health care providers must first understand the immunization-related concerns of parents and understand the influences that can lead to misinformation or misperceptions about the safety and effectiveness of vaccines. He suggested that providers should attempt to establish an open, non-confrontational dialogue at an early stage, and provide unambiguous, easily understandable answers about known adverse events and provide accurate information about vaccination. Diekema (2012) concluded that physicians represent the best opportunity to influence the vaccine-hesitant. He suggested that they listen respectfully, acknowledge parental concerns, and provide accurate information about both risks and benefits. Opel *et al.* (2009) further expanded on this theme, by suggesting that physicians are most likely to be effective if they have established trust, made clear that they share a common goal with the parent (the welfare of the child), and developed a positive relationship by displaying a willingness to listen respectfully and attend to parental concerns.

A number of researchers have concluded that data alone may be insufficient to convince vaccine-hesitant parents. Several have suggested that a compelling story is more likely to persuade the listening parent (Opel 2009, Diekema 2012, Healy 2011, Kempe 2011). Personal statements by physicians about what they would do for their own children, or about their personal experiences with vaccine safety among their patients have been suggested as highly effective strategies in convincing skeptical parents to vaccinate their children (Kempe 2011). Another strategy offered by Shelby (2013) is to recruit pro-vaccine parents to serve as peer to peer “vaccine ambassadors.”

Guidelines for communicating with vaccine-hesitant parents have been published, and offer suggestions for ways in which health care providers may effectively respond to vaccine concerns and questions. They emphasize that providers should listen carefully and respectfully to parents’ concerns and be knowledgeable and honest in discussing what is known about the associated risks and benefits. Providers are encouraged to try to understand the parent’s concerns and take steps to correct misperceptions and misinformation, to offer to refer parents to reputable sources of additional information, to take steps to reduce pain of injection, to permit a schedule of immunization that minimizes number of injections at a single visit, and to work with parents to eliminate or minimize financial barriers (Diekema 2005). To be most effective, provider communication with vaccine-hesitant parents may need to be customized to the specific parent’s position and concerns. A study published in 2012 (Leask) offers a framework for tailoring communication strategies, and provides examples of suggested dialogue for unquestioning and cautious vaccine acceptors, hesitant, and refusing parents. The authors also point out that converting a vaccine-hesitant parent to vaccine acceptance may require more than one discussion. A recently developed and validated vaccine-hesitancy screening instrument, the Parent Attitudes about Childhood Vaccines survey (Opel 2011, Opel 2013), may be helpful to practitioners as a way to quickly assess parents’ vaccine concerns.

One likely challenge to the physician’s primary role in reassuring vaccine-hesitant parents is the amount of time involved. In most cases, a conversation with a hesitant parent is likely to be productive but may be challenging and time-consuming, and may require more than a single conversation (Domachowske 2013). Lack of physician knowledge about vaccine safety evidence

and lack of physician comfort in communications about possible risk have been cited as additional barriers to effective physician communication with vaccine-hesitant parents (Kempe 2011).

PARENTAL ATTITUDES AND CONCERNS IN KANSAS

Previous Studies in Kansas

One published, peer-reviewed study of Kansas parent perceptions related to childhood immunization was identified (Frederickson, 2004). In that study, focus groups were conducted in 1998 with parents and providers in six Kansas communities. Participants were asked about trusted sources of information about immunizations, what information parents wanted or needed, concerns related to vaccines, and beliefs about vaccines and the diseases they prevented. Some parents in this study expressed concerns with specific vaccines, most commonly hepatitis B or varicella. Some parents believed that natural immunity acquired from having the disease was preferable to that acquired from vaccines. Several parents who had refused vaccines for their children believed that breastfeeding and keeping children out of day care settings would protect their children from most vaccine-preventable diseases. The majority of parents indicated that they trusted the information given to them by their physicians, and that they wanted factual information delivered “without spin.” All parents said that they were open to discussion with providers but wanted a concerned listener approach from the provider rather than judgment or admonishment. In this study, all parents preferred spoken information from providers as opposed to handouts or printed materials.

In 2008, the Kansas Health Institute conducted a qualitative study to identify perceived barriers to childhood immunization among three groups of subjects: private provider clinics, local health departments and parents of children aged 0 to 35 months (Ayers, 2008). Parents interviewed in the study were randomly selected from patient rosters of the participating provider clinics. Fifty-five parents were interviewed individually by telephone; each interview included an assessment of the child’s immunization (by parent report), parent satisfaction with the immunization process, barriers and facilitating factors to timely immunization and suggestions for improvements to the immunization system. In that study, parents most frequently identified

scheduling inconvenience a barrier to timely immunization of their children, but followed that closely with concerns related to the overall number of injections, the number of injections given during a single visit, the physical pain experienced by the child and the emotional pain experienced by parents. Parents expressed frustration that providers sometimes appeared insensitive to children's pain reactions, and that providers sometimes failed to fully explain the immunization schedule, the need for all recommended immunizations, and what parents should expect during and following the immunization. Parents stressed that they preferred to receive education from providers through direct conversations rather than handouts or printed materials.

Legislative Testimony

In recent years, several attempts have been made to modify Kansas law to allow for exemption from childhood immunization requirements on the basis of parents' philosophical beliefs. In the most recent attempt, House Bill 2094 was introduced in the Kansas House of Representatives Health and Human Services Committee in January of 2012. Although the bill later died in committee, a number of proponents and opponents presented testimony in support of their positions. The testimony presented is likely to represent views held by small numbers of parents with strong opinions and should not be considered generalizable to other Kansas parents, but it does provide additional insight into vaccine concerns held by some Kansas parents. Parents who testified in support of the bill most often cited concerns about vaccine safety and effectiveness, and experiences with adverse health reactions thought to be related to immunization. A lesser emphasis was placed on the concern that vaccine mandates interfere with parents' rights to make health care decisions for their children.

Kansas Kindergarten Immunization Coverage Survey Findings

Each year, staff within the Bureau of Epidemiology and Public Health Informatics at KDHE collect and analyze immunization records of Kansas children enrolled in kindergarten in either a public or private school setting during that year (Lawlor 2012, Lawlor 2013). The primary purpose of the survey is to monitor immunization coverage rates among Kansas children as they enter school. Designated school coordinators are instructed to submit copies of immunization records and immunization exemption records of kindergarten students. Data are then analyzed

and weighted to produce estimates of kindergarten student immunization coverage by school district and county.

In the state of Kansas, two legal alternatives to full vaccination at school entry exist – exemption based upon medical reasons, or exemptions due to religious beliefs. To receive a medical exemption, a physician must sign an exemption form stating the reason for the exemption and the specific vaccines to be exempted. Religious exemptions require that a parent or guardian write a statement explaining that the child is affiliated with a religious denomination whose teachings are opposed to immunization. Identification of the specific religious denomination is not required, and no certification by clergy is requested.

During the 2011-2012 school year, 494 Kansas kindergarteners (1.3 percent of the total kindergarten population) were reported as having an immunization exemption. Of those exemptions, 364 (73.7 percent) were categorized as religious; the remaining 130 were medical. Exemptions were scattered throughout the state; however, in the two most recent annual surveys, counties with the largest percentages of exempt students have been predominantly in the eastern half of Kansas (Figures 1 and 2). Survey results indicate that numbers of kindergarten students with immunization exemptions has increased slightly over the past three years (Table 3).

Figure 1. Percent of Kindergarteners Exempt at Reporting Schools by County, 2012-2013

(Includes children enrolled at both public and private schools)

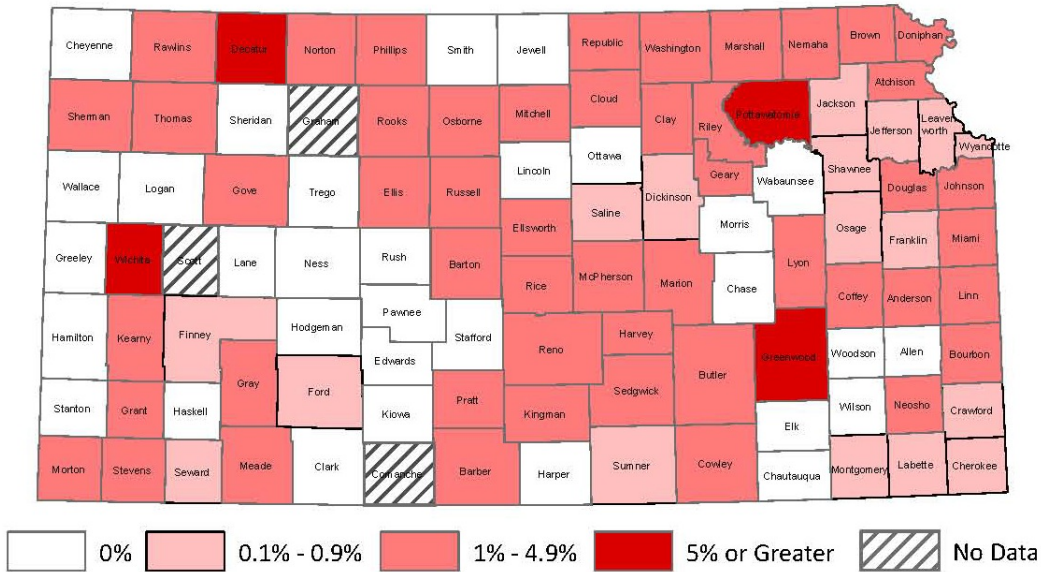
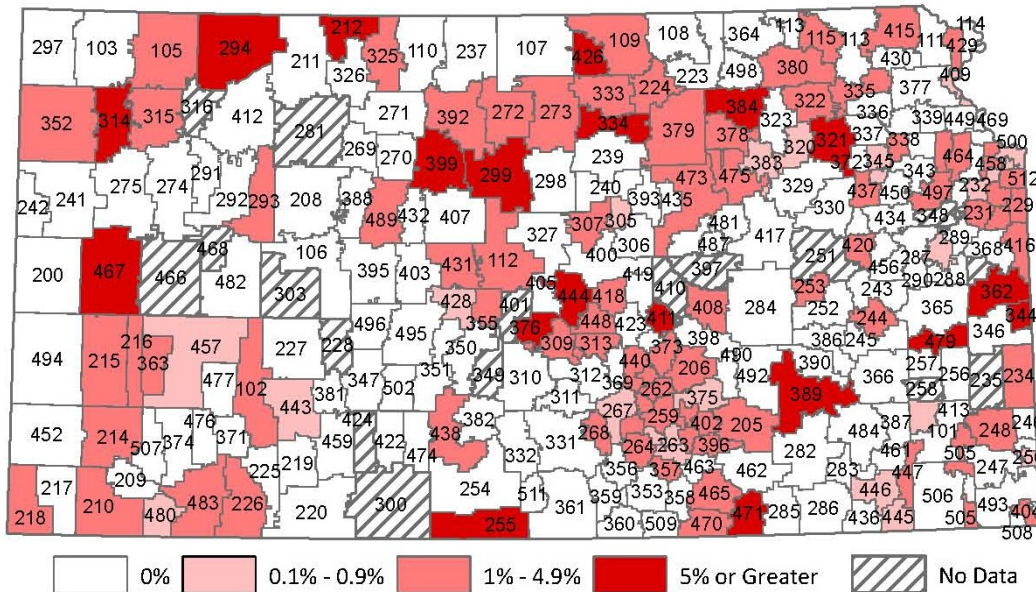


Figure 2. Percent of Kindergarteners Exempt at Submitting Public Schools by District, 2012-2013



Source of maps: KDHE, Lawlor, Elizabeth. Kindergarten Immunization Coverage Survey, School Year 2012-13

Table 3. Religious and Medical Exemptions Among Kansas Kindergarten Students

	2010-11 School Year	2011-12 School Year	2012-13 School Year
Number of schools reporting	800	794	729
Number of children enrolled in kindergarten at reporting schools	38,496	38,402	35,203
Religious exemptions	287	364	363
Medical exemptions	111	130	118
Total exemptions, (number, %)	398 (1.0%)	494 (1.3%)	481 (1.4%)

Staff from the Kansas Health Institute reviewed a convenience sample of the exemption records collected by the 2011-2012 Kindergarten Immunization Coverage Survey. The majority of children for whom non-medical exemptions were claimed had received some, but not all of the recommended immunizations. A small number of exemption claims included comments written by a parent; examples are listed below.

- "We do not immunize our children, in accordance with our religious beliefs"
- "I exercise my right to withhold immunizations for religious reasons"
- "Immunizations show a lack of faith in God's creation, the human body, and immune system."
- "The Bible states that you are not supposed to mix blood with blood, and when you examine the components of shots, there are several different things included that I do not feel are natural to mix with my children's blood. I believe God equipped us all with a functioning immune system that, when backed with proper nutrition, is all that is necessary"
- "We do not believe in immunizations"
- "As of today's date, I have chosen not to give the 2nd dose of the chicken pox vaccine to my child. After research, the benefits do not outweigh the risks."
- "I choose not to complete immunizations for [child's name]."

While some of the comments reference religious beliefs, others were less specific about the basis for the exemption. Kansas does not require that a parent claiming a religious exemption provide any information about denominational affiliation or specific basis for the objection to immunization. Consequently, it is unclear how many of these exemption claims are actually based upon specific religious doctrine versus philosophical or personal beliefs objections that are being claimed under the religious exemption option and should not be allowable under current Kansas laws.

Kansas 2012 Behavioral Risk Factor Surveillance Survey Findings

At the request of the Immunize Kansas Kids coalition, a state-specific module of questions related to childhood immunization was added to the 2012 Kansas Behavioral Risk Factor Surveillance System (BRFSS) survey (KDHE). Utilizing a randomly selected sample of Kansas adults and a telephone interview methodology, parents of children age 0 to 17 years were asked about their level of confidence in the safety of routine childhood vaccines, what their greatest vaccine-related concerns were (if any), their most important source of vaccine-related information, and the extent to which a selected child in the household had received all immunizations recommended by the child's health care provider. A total of 1,301 Kansas parents responded to the questions. Results are presented in Table 4 below.

Results show that a small majority of Kansas parents (58.9 percent) have high levels of confidence in vaccine safety. Among those who had any concerns about childhood vaccine, side effects such as fever and pain, and the number of vaccines given (too many) were most often cited. Health care providers were identified by more than two-thirds (68.5 percent) of parents as the most important source of immunization information.

Table 4. 2012 Kansas BRFSS – Parental Responses to Childhood Immunization Questions

Question	Weighted Percentage	95% Confidence Interval
<i>In general, how confident are you in the safety of routine childhood vaccines?</i>		
Not at all confident	4.6%	3.2 to 6.0%
A little confident	8.5%	6.5 to 10.5%
Moderately confident	28.0%	25.1 to 30.9%
Very confident	58.9%	55.7 to 62.1%
<i>What is your greatest concern about childhood vaccines, if any?</i>		
Too many vaccines given	12.1%	9.9 to 14.3%
Vaccines are not safe	3.1%	1.9 to 4.3%
Vaccines cause diseases such as autism	7.1%	5.5 to 8.7%
Vaccines are not necessary	1.8%	0.8 to 2.7%
Vaccines cause side effects, such as fever and pain	13.0%	10.9 to 15.0%
No concerns	55.9%	52.6 to 59.2%
Other	7.1%	5.4 to 8.8%
<i>What is the most important source of information that has helped you make decisions about vaccinating your child?</i>		
Health care provider	68.5%	65.4 to 71.7%
Media such as magazines, television or radio	5.5%	4.0 to 7.1%
Internet	7.3%	5.5 to 9.2%
Friends or family	14.2%	11.8 to 16.6%
Other	4.4%	3.1 to 5.7%
<i>Have you obtained ALL age appropriate immunizations or shots as recommended by your child's health care provider? (Asked about a specific child selected from within the household)</i>		
Yes, all age appropriate	94.8%	93.3 to 96.2%
Yes, some age appropriate	2.4%	1.5 to 3.4%
No	2.6%	1.5 to 3.7%
Health care provider has not recommended any immunizations	0%	0.0 to 0.1%
Health care provider has specifically stated not to obtain any immunizations	0.1%	0.0 to 0.4%

Findings from Focus Groups and Interviews with Kansas Parents

In this study, one in-person focus group was conducted with eight participants, and individual interviews were conducted by telephone with an additional five participants. Informed consent was reviewed and affirmed with all participants prior to beginning the data collection process. In addition, all participants were asked to complete a short questionnaire including demographic and vaccine hesitancy information.

Characteristics of the study participants are summarized in Table 5. All study participants were female, between the ages of 25 and 39 years, and predominantly white, non-Hispanic. The majority were college graduates.

Table 5. Characteristics of Kansas study participants (n=12)

Characteristic	Results
Age (in years)	Mean: 31.3 years, (range 24 to 39)
Number of children under age 18 in the home	Mean: 2.1 (range 1 to 5)
Gender, female	100% (n = 12)
Race, Caucasian	100% (n = 12)
Ethnicity, non-Hispanic	92% (n=1)
Educational attainment	
High School	8% (n=1)
Associate degree, Technical School or some College	17% (n=2)
Bachelor degree	42% (n=5)
Graduate degree	33% (n=4)
Household income	
Less than \$30,000	8% (n=1)
\$30,000-49,999	25% (n=3)
\$50,000-69,999	25% (n=3)
\$70,000 or more	42% (n=5)
One or more child attends daycare outside of home	58% (n=7)
One or more child attends school outside of home	75% (n=9)
Plans for vaccinating youngest child	
All immunizations, by recommended schedule	17% (n=2)
All immunizations, by alternate schedule	0% (n=0)
Selective immunization, not all recommended	50% (n=6)

No immunization	8% (n=1)
Not sure	25% (n=3)

The short questionnaire also included the Parent Attitudes about Childhood Vaccines (PACV) Survey, a validated 15-item question panel designed to allow providers to rapidly assess levels of parental vaccine hesitancy (Opel 2013). It is intended to be a self-administered paper survey that can be completed in less than five minutes, with a simple numeric scoring system. Possible scores range from 0 to 100. Questions from the PACV, and responses of study participants are shown in Table 6.

Table 6. The Parent Attitudes about Childhood Vaccines Survey: Responses of Kansas Study Participants (n=12)

Question	Response Options	Vaccine Hesitancy Scoring	% Participants with Vaccine-hesitant response*
Have you ever delayed having your child get a shot for reasons other than illness or allergy?	Yes/No/Don't know	Yes= 2 points No = 0 Don't know treated as missing	82%
Have you ever decided not to have your child get a shot for reasons other than illness or allergy?	Yes/No/Don't know	Yes= 2 points No = 0 Don't know treated as missing	82%
If you had another infant today, would you want him/her to get all the recommended shots?	Yes/No/Don't know	Yes = 0 points No = 2 points Don't know = 1 point	82%
How sure are you that following the recommended shot schedule is a good idea for your child?	1-10, Not At All (1) to Completely Sure (10) 0-7=vaccine hesitant	0-5 = 2 points 6-7 = 1 point 8-10 = 0 points	91%
Children get more shots than are good for them.	Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree	Agree, strongly agree = 2 points Disagree, strongly disagree=0 points Not sure = 1 point	91%
I believe that many of the illnesses shots prevent are severe.	Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree	Agree, strongly agree = 2 points Disagree, strongly disagree=0 points Not sure = 1 point	36%

It is better for my child to develop immunity by getting sick than to get a shot.	Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree	Agree, strongly agree = 2 points Disagree, strongly disagree=0 points Not sure = 1 point	91%
Question	Response Options	Vaccine Hesitancy Scoring	%Participants with Vaccine-hesitant response*
It is better for children to get fewer vaccines at the same time.	Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree	Agree, strongly agree = 2 points Disagree, strongly disagree=0 points Not sure = 1 point	91%
How concerned are you that your child might have a serious side effect from a shot?	Not at all, Not too , Not sure, Somewhat, Very	Somewhat or very = 2 points Not at all, not too = 0 points Not sure = 1 point	91%
How concerned are you that any one of the childhood shots might not be safe?	Not at all, Not too , Not sure, Somewhat, Very	Somewhat or very = 2 points Not at all, not too = 0 points Not sure = 1 point	91%
How concerned are you that a shot might not prevent the disease?	Not at all, Not too , Not sure, Somewhat, Very	Somewhat or very = 2 points Not at all, not too = 0 points Not sure = 1 point	82%
Overall, how hesitant about childhood shots would you consider yourself to be?	Not at all, Not too, Not sure, Somewhat, Very	Somewhat or very = 2 points Not at all, not too = 0 points Not sure = 1 point	91%
I trust the information I receive about shots.	Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree	Agree, strongly agree = 2 points Disagree, strongly disagree=0 points Not sure = 1 point	82%
I am able to openly discuss my concerns about shots with my child's doctor.	Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree	Agree, strongly agree = 0 points Disagree, strongly disagree=2 points Not sure = 1 point	9%
All things considered, how much do you trust your child's doctor?	1-10, Do not trust at all (1) to Trust completely (10) 6-10 = vaccine	0-5 = 2 points 6-7 = 1 point 8-10 = 0 points	22%

	hesitant		
Question	Response Options	Vaccine Hesitancy Scoring	%Participants with Vaccine-hesitant response*
Vaccine Hesitancy Scores, Possible Range 0 -100	Possible range, 0-100	To obtain total standardized score, sum points from each question, multiply by 100/30	Mean: 65.5 Median: 70 Range: 0 to 87

*Responses that indicate vaccine hesitancy are in bold

Words Parents Associated with Immunization

The focus group discussion and interviews were begun with an ice-breaker question in which parents were asked to describe what immediately comes to mind when thinking of childhood immunization. Responses were predominantly negative, and included words such as *stressful*, *controversial*, *side effects*, *safety*, *coercion*, *big business*, *suffering*, *childhood diseases*, and *lawsuits*, *danger*, *necessary evil*, and *fear*. A minority of responses were more neutral, including words such as *getting ready for school*, *routine* and *consistent*.

Effectiveness of Childhood Vaccines

Participants were asked to share their thoughts about the effectiveness of childhood vaccines at preventing disease. Most participants identified at least some level of doubt about effectiveness of one or more vaccines. Reasons for doubt of effectiveness included outbreaks of disease among previously-vaccinated children, frequent additions of more booster doses to the recommended immunization schedule in an attempt to maintain immunity levels, historical examples of flu vaccines that have had low effectiveness rates, and efficacy rates published by CDC that indicate some vaccines are only 70 percent effective. Two participants were more positive, indicating that they felt that vaccines were generally effective. One commented that while vaccines are generally effective, they are not foolproof, and suggested that people may have misconceptions about effectiveness.

Participants were asked if there were specific vaccines that they thought were less effective. Pertussis was frequently identified – parents were aware that the vaccine formulation had been modified to reduce adverse side effects but that the result was also shorter duration of immunity

and perhaps lowered effectiveness. Varicella, influenza and HPV vaccines were also cited as having lower effectiveness.

Importance of Vaccines for Protecting Own Child's Health

Participants were asked to comment on how important they thought childhood immunizations are for protecting the health of their own children. Although most participants acknowledged some level of benefit gained through having an immunized population, they were less positive about the importance of immunizing their own children. Some indicated that they felt that some of the recommended immunizations are important, but not everything that is currently included on the recommended schedule is necessary, and that the individual child's situation and potential for exposure was a consideration. One mother went as far as to say, "not immunizing is one of the most important things I can do to protect my child's health." Others expressed the belief they could more effectively protect the health of their children through good parenting practices such as extended breastfeeding, hand washing and isolation without exposing their child to a possible adverse reaction to a vaccine. Some parents indicated that though they were not entirely anti-vaccine, they had concerns about the recommended schedule and number of vaccines, and preferred to delay or immunize selectively for those vaccines deemed to be most safe and important.

Importance of Immunization to Protect Health of Other Children

Next, participants were asked for their thoughts about the importance of immunizing their children in order to help protect the health of other children. While participants generally understood the concept of herd immunity (protecting individuals without established immunity by maintaining high immunization rates in the population), most also rejected the notion as a reason for immunizing their own children. Some felt that encouraging individuals to immunize for the sake of protecting others was coercive. Others suggested that the concept is flawed because of waning immunity among older segments of the population, leaving widespread gaps in coverage. Examples were cited where outbreaks originated among vaccinated children, further casting doubt upon the usefulness of the herd immunity concept. Some expressed the opinion that by keeping their own children home when ill they are able to protect others in the community from exposure. The most consistent reaction among participants, however, was the

sentiment that parents have an obligation to place higher priority on doing what is right for their own children rather than on doing what might benefit the larger community.

Vaccine Safety

Among the parents that participated in this study, confidence in the safety of vaccines for their child was low. Some said that for most children in good health, vaccines were probably safe. Others were less sure. Many expressed frustration that there is no way to know before immunizing which children are more likely to experience adverse reactions, and to which vaccines. Several participants cited examples of family members or close friends who were believed to have had a significant adverse vaccine reaction. In addition to safety concerns with individual vaccines, several parents expressed concerns that the safety of the current administration schedule and combined vaccines are untested and unknown.

When asked about specific adverse outcomes of concern, most participants focused on neurological problems. Participants were generally aware that the study linking the measles, mumps and rubella (MMR) vaccination to autism had been discredited, but expressed continued concerns about problems such as neurological deficits and “brain swelling.” Allergies and immune system complications were also mentioned.

When asked about whether there were specific vaccines that were most worrisome, no consistent patterns emerged. Participants indicated safety concerns related to chemical additives in vaccines as well as the concerns related to the antigens.

Participants were generally aware of the national Vaccine Adverse Event Reporting System (VAERS) and the National Vaccine Injury Compensation Program (VICP), and many had reviewed the data available in these systems. They also expressed the belief that many adverse reactions to vaccines are probably either not recognized or not reported. Nevertheless, awareness of the reactions that have been reported has likely contributed to safety concerns among the parents who participated in this study.

Discussion of Vaccine Concerns with Physician

Nearly all participants indicated that they were comfortable in discussing with their child's doctor questions and concerns about immunization. Many described respectful, open discussions that had taken place. As one mother put it, "if I could not have a discussion with my doctor, I would find another doctor." Some parents did feel that their child's physician had not kept up with current research, and was not able to answer their questions in a satisfactory manner. Many parents reported that after a discussion of possible benefits and risks, their physician was accepting of their right to make the final immunization decision.

Several participants reported less positive relationships with nursing staff in their physician's office. Participants described experiences where nurses had been pushy, harshly critical and judgmental of their decisions to refuse an immunization. A couple of mothers reported that they had changed or were considering changing physicians because of difficult encounters with nursing staff in the office.

Sources of Information

Study participants were asked what sources of information they trusted when they had questions or concerns about immunizing their children. Nearly all agreed that they trusted their physician, although some mentioned that their physician was not always familiar with current research and able to answer their questions satisfactorily. Peer-reviewed studies were mentioned by several as a trusted information source, although some participants indicated that they would still look at funding sources of the studies, and consider potential for bias. Participants in the group discussion agreed that they trusted the opinions and experiences of other parents. CDC, the American Academy of Pediatrics website, and the National Vaccine Information Center were mentioned as trusted sources. Other sources mentioned, with mixed reactions from other participants, were books from well-known doctors such as Dr. Sears and Dr. Oz. A few participants mentioned that they compare immunization recommendations from other countries to those of the U.S.

Participants were generally aware of the need to carefully screen information and confirm reliability and accuracy of the material. Following up by checking sources of media articles was

suggested as one method for doing so. Looking at funding sources was another. Many indicated that they are cautious in evaluating information found on the Internet, and try to avoid extreme or anecdotal information.

Participants were asked if there were other sources of information that they wished they had access to. Peer-reviewed journal articles were mentioned frequently. A small number of focus group participants currently had access through their employment or academic connections; other parents expressed interest and envy.

Unanswered Questions

Participants were asked to share their biggest unanswered questions or concerns about childhood immunization. Their responses are listed below:

- “Long-term effects that have not yet been identified or studied. The safety of the current schedule, with so many antigens given all together, has not been adequately studied. What will they be telling us in 10-15 years?”
- “Uncertainty about individual risk – I wish I could know whether my child would have a [adverse] reaction. I can always do it later; I can’t undo it if we have a problem. If I were to immunize my child and he/she had a bad reaction, I couldn’t live with it.”
- “I wish I had more information about vaccination schedules and practices in use in other industrialized nations. What are they doing differently from the U.S., and what could be learned from that? A study found that in Japan, where Pertussis vaccine is not given until two years of age, sudden infant death rates are lower.”
- “I would like to have more information about breastfeeding possibly interfering with immune responses to vaccination and humoral immunity acquired through breast milk.”
- “I would like to see a large study of U.S. children, comparing long-term health outcomes for vaccinated and non-vaccinated children.”

- “I’m frustrated with the backlash for asking questions – that’s what science is about.”
- “The way in which vaccine injuries are handled is a concern. There is no way to prove that an injury has occurred as a result of vaccination, and that is frustrating. Even in cases where there is no question that an injury has resulted, the federal compensation is not adequate to cover the associated cost for the victim. It is frustrating that manufacturers are not held responsible for injuries related to their products.”
- “Not having access to single-antigen vaccines so that I can protect my child against the diseases that I feel are important, without having to give them unnecessary antigens.”
- “I think, overall, it’s about weighing the risks and benefits. It’s a hard thing to do. It’s impossible to know if I’m making the right decision for my child. It’s a complex decision. So much of the conversation is fear-driven (on both sides). What is the actual risk?”

Other Comments from Study Participants

In addition to the responses to the pre-defined questions, a few additional themes emerged from discussions.

Several participants expressed concern with ‘one-size-fits-all’ approaches to immunization, and indicated that they would prefer more individualized consideration of potential risk for exposure to disease, risk for adverse reactions, and testing of antibody titer levels prior to deciding to immunize. One commented that the CDC looks at issues from statistical and population health perspectives, which are not always family-friendly. Another mother said, “What makes sense in terms of protecting the population may not be best for my child.”

While most of the study participants felt that at least some immunizations were important to protecting their children’s health, many commented that they felt not everything that is currently included on the immunization schedule is necessary. Participants questioned the rationale for vaccinating all newborns against Hepatitis B (a blood-borne pathogen, most commonly

transmitted to newborns through a mother that is infected), rather than testing mother and vaccinating selectively as indicated. The need for immunizing against varicella was also questioned due to the perception that risks of complications associated with having the disease were low.

Within the group of mothers that participated in this study, several expressed the sense that through extended breastfeeding and vigilant parenting practices, they could do a better job of protecting child from disease than by vaccinating.

Distrust of motivation was also a common theme. Participants commented about the pharmaceutical industry and perhaps doctors profiting from immunization. One participant, whose father was a physician, suggested that the current immunization schedule is designed for the convenience of the physician rather than what is really best for the child.

DISCUSSION AND POSSIBLE OPPORTUNITIES

In this study, Kansas-specific findings from a small number of parental interviews and focus groups parallel and complement those from published reports of studies conducted in other locations. A small number of Kansas parents are expressing concerns and hesitancy about vaccinating their children in accordance with the schedule recommended by the CDC. Most are not adamantly anti-vaccination, but have varying levels of discomfort or uncertainty about the best course of action for their individual child. The parents who participated in this study might be characterized as generally well-educated, well-informed and highly vigilant parents who are sincerely trying to make the best decisions on behalf of their children. They seek answers to their questions and want open, honest, respectful dialogue with their children's physicians. While they consistently expressed a high level of trust in their physicians, the majority were also confident in their own abilities to conduct additional research and verbalized a desire to be supported and respected in making their own decisions after careful consideration of the possible risks and benefits associated with immunization.

Reports in the published literature suggest that vaccine-hesitant parents want physicians who are well-informed about immunization, prepared to discuss the risks and benefits, and honest about the possible risks. When doctors dismiss or refuse to acknowledge concerns and possible risks, they lose credibility with vaccine-hesitant parents and those parents may either seek out another physician more sympathetic to their views or decide to refuse vaccination for their child altogether.

Parents in this study frequently indicated that they are seeking a better understanding of the potential risks and benefits of each individual vaccine, the potential risks that their child might be exposed and contract a vaccine-preventable disease, the potential severity and complications of vaccine-preventable diseases, and the risks that their individual child might experience an adverse reaction resulting from immunization. They voiced frustration with what they view as a ‘one-size-fits-all’ approach to childhood immunization that is promoted by public health policy-makers and many health care providers. Many have conducted substantial research on their own, turning to sources they perceived to be credible, such as the CDC, the American Academy of Pediatrics, peer-reviewed study reports, and vaccine manufacturers’ package inserts.

Recruitment of parent participation in this study was more challenging than initially anticipated. It is likely that a lack of trust and a fear of stigmatization prevented other vaccine-hesitant parents in the selected communities from stepping forward. Some of those who did participate commented that they knew of many other parents in their communities who had similar concerns about childhood immunization, but were reluctant to participate in this study due to uncertainty about how the collected information would be used and fear that their comments would be disclosed publicly and result in stigmatization. Participants who did participate in this study expressed gratitude for the opportunity to have their voices heard, and appreciation for the opportunity to participate and contribute to a constructive dialogue.

Possible Opportunities

From both the published literature and comments shared by Kansas parents who participated in this study, a number of possible opportunities and approaches to effectively addressing the concerns of vaccine-hesitant parents can be identified. Primary care physicians are a central

resource in addressing parents' vaccine questions. Overwhelmingly, vaccine-hesitant parents still trust their children's physicians and turn to them for information. To be effective in answering parents' questions and addressing concerns, physicians must be familiar with current evidence about risks and effectiveness, and willing to discuss parents' concerns with a respectful, honest approach. From published studies and parents who participated in this study, several suggestions have been offered that physicians may find helpful in their interactions with vaccine-hesitant parents, and are included here for consideration. Those include:

- Create an environment of comforting reassurance for the administration of immunizations. Implement measures to reduce the pain associated with injections, and offer suggestions for steps that parents may take to reduce the discomfort that is sometimes experienced following immunization.
- Listen respectfully to parents' questions and concerns, and attempt to provide honest, straightforward answers. Recognize that providing scientific data alone may not be sufficient, and that more than one discussion may be needed before a parent feels that all questions have been adequately addressed and he or she is ready to make a decision. The use of personal experience has been shown to be powerful; parents often appreciate hearing what a physician would do for his/her own child, or what a physician has personally seen or encountered in his practice. The identification of pro-vaccine parents who are willing to talk with vaccine-hesitant parents on a peer-to-peer basis has also been shown to be effective in reassuring parents.
- Acknowledge that there are some risks of adverse reactions to vaccines. Be prepared to discuss with parents what those risks are, how frequently such reactions occur, whether there is any way to anticipate the level of risk for an individual child, and how adverse reactions might be mitigated or managed.
- Physicians may wish to be prepared to help parents prioritize the importance of specific immunizations, and possible alternative schedules for administration. In some cases, working with a parent to consider which immunizations are most important to

protecting a child's health, and when the child is most likely to be at risk for exposure to disease, may result in a child receiving at least some immunizations rather than none.

- Physicians are also in a position to help guide parents who want to do more research on their own to reliable and credible sources of information. Handouts offering suggested information sources and guidelines for assessing the validity of information could be used to help parents make informed decisions and avoid misleading information.
- The recent development and testing of a short questionnaire to assess parental vaccine hesitancy offers physicians a way to quickly identify areas of concern and tailor immunization discussions with parents. Physicians may want to consider implementing use of this screening tool in their practices.
- Finally, physicians may want to provide guidance and direction to nursing staff in their practices about how to interact with vaccine-hesitant parents. Reports of parents who participated in this study suggest that while most had a positive relationship with their child's physician, many had experienced less positive encounters with nurses in the physician's office.

Professional associations and immunization advocacy organizations could assist in addressing vaccine-hesitancy by providing physicians with educational opportunities and resources that allow them to stay current with recent research findings related to childhood immunization, and suggested techniques for interacting with vaccine-hesitant parents. Additionally, the development and distribution of educational materials and resources designed for physicians to offer to vaccine-hesitant parents is a role that these groups could assist with.

At the national level, policymakers and immunization experts responsible for promulgating immunization recommendations may need to carefully consider the potential unintended consequences of continuing to add more vaccines and additional doses to the immunization

schedule. Findings from this study and others suggest that increasing numbers of parents view the current schedule as excessive and perhaps unnecessary, and the delicate balance between perceived benefits and risk may be at a tipping point with many parents. Lantos (2010, 2013) suggests that vaccine hesitancy and under-immunization exist in a semi-stable equilibrium with outbreaks of infectious disease. He proposes that during periods when immunization rates are relatively high and disease rates low, parents worry more about side effects than about disease. When immunization rates go down, and rates of disease increase, parents worry less about side effects of immunization and more about complications of the disease. It was clear from comments made by parents who participated in our study that most are attempting to weigh the possible risks and benefits of immunizing their children. Adding more immunizations to the recommended schedule, particularly if parents perceive that either exposure is unlikely or the disease is not severe, may result in more parents who perceive the risks associated with immunization to outweigh the possible benefits and opt not to follow the recommended schedule.

Several parents in our study expressed frustration with lack of research on the long-term effectiveness and safety administering immunization in accordance with the currently recommended schedule. A recent report from the Institute of Medicine (2013) assessed the scientific evidence of health outcomes related to the current immunization schedule, and found existing research insufficient to adequately resolve questions surrounding safety and effectiveness. They recommended that the U.S. Department of Health and Human Services incorporate study of the safety of the overall childhood immunization schedule into their research priorities. Implementation of this recommendation could provide the information needed to definitively address parents' concerns.

STUDY LIMITATIONS

A small number of self-selected parents were interviewed as part of this study. Although their comments are invaluable in providing insight into the factors that contribute to parental vaccine-hesitancy in Kansas, their perspectives may not be representative of other vaccine-hesitant parents, either within or outside of Kansas. Study participants were predominantly

white, non-Hispanic, with educational and income levels higher than the general population in Kansas.

CONCLUSIONS

Childhood immunization against vaccine-preventable diseases has been a public health success, achieving dramatic reductions in rates of childhood death and disability. Maintaining high rates of immunization coverage among children is essential to sustaining this accomplishment, but will not be possible if increasing numbers of parents doubt that immunization is in their child's best interest.

A general erosion of trust in government and business, declining parental familiarity with the potentially devastating adverse consequences of vaccine-preventable diseases, media attention to claims of vaccine-associated injuries, a faulty scientific study linking childhood vaccines to autism, abundant access to information and misinformation, and an increasingly complex schedule of recommended immunizations and boosters have all contributed to a growing loss of parental confidence in the safety and necessity of childhood immunizations. That confidence, once lost, may be difficult to restore.

Across the U.S., increasing numbers of parents are raising questions about the safety, risks and benefits of the immunizations being recommended for their children, and they are seeking answers to those questions. Studies, including this one, have found those vaccine-hesitant parents to be predominantly well-educated and informed parents who are trying to make the best possible decisions for their children.

At present, the number of vaccine-hesitant parents is relatively small, and the number who refuse all vaccines for their children even smaller. If public health and health care practitioners wish to maintain high immunization coverage rates, they will need to be responsive to the questions and concerns raised by vaccine-hesitant parents. A number of possible options have been suggested in this report.

A key finding of this study is that vaccine-hesitant parents who participated in this study consistently said that they trust their child's physician and value his/her advice. Although discussions with vaccine-hesitant parents take time and add to demands on practitioners' already-

busy schedules, they are also an opportunity to strengthen the provider/patient relationship, to encourage parental participation in the decision-making process, and to ensure that parents have credible information and resources upon which to base their decisions.

APPENDIX A: ABBREVIATIONS

BRFSS — Behavioral Risk Factor Surveillance System

CDC — Centers for Disease Control and Prevention

IOM — Institute of Medicine

KDHE — Kansas Department of Health and Environment

KHI — Kansas Health Institute

NCSL — National Conference of State Legislatures

NNII — National Network for Immunization Information

PACV — Parent Attitudes about Childhood Vaccines Survey

VAERS — Vaccine Adverse Event Reporting System

VICP — Vaccine Injury Compensation Program

APPENDIX B: FOCUS GROUP QUESTIONNAIRE



IMMUNIZE KANSAS KIDS

REGISTRATION FORM

1. How many children under the age of 18 years live in your household? _____
2. Do any of your children attend daycare outside of your home? _____ Yes _____ No
3. Do any of your children attend school outside the home? _____ Yes _____ No
4. Which of the following best describes your plans for vaccinating your youngest child?
(check one)
 - I intend to have my child receive all of the recommended vaccines as scheduled.
 - I intend to have my child receive all of the recommended vaccines but will space out or delay some of them.
 - I intend to have my child receive some but not all of the recommended vaccines.
 - I intend to have my child receive none of the recommended vaccines.
 - I'm not sure
5. If your child(ren) is/are immunized, where do they most often obtain their immunizations?
 - The child's doctor's office
 - The local health department
 - Other (specify)_____
6. Have you ever delayed having your child get a shot for reasons other than illness or allergy?
 - Yes
 - No
 - Don't know

7. Have you ever decided not to have your child get a shot for reasons other than illness or allergy?

- Yes No Don't know

8. If you had another infant today, would you want him/her to get all the recommended shots?

- Yes No Don't know

9. How sure are you that following the recommended shot schedule is a good idea for your child?

(Circle the number that represents your choice)									
Not at all sure									Completely sure
1	2	3	4	5	6	7	8	9	10

10. Children get more shots than are good for them.

- Strongly agree Agree Not sure Disagree Strongly disagree

11. I believe that many of the illnesses shots prevent are severe.

- Strongly agree Agree Not sure Disagree Strongly disagree

12. It is better for my child to develop immunity by getting sick than to get a shot.

- Strongly agree Agree Not sure Disagree Strongly disagree

13. It is better for children to get fewer vaccines at the same time.

- Strongly agree Agree Not sure Disagree Strongly disagree

14. How concerned are you that your child might have a serious side effect from a shot?

- Not at all concerned Not too concerned Not sure

- Somewhat concerned Very Concerned

15. How concerned are you that any one of the childhood shots might not be safe?

- Not at all concerned Not too concerned Not sure

- Somewhat concerned Very Concerned

16. How concerned are you that a shot might not prevent the disease?

- Not at all concerned Not too concerned Not sure
 Somewhat concerned Very Concerned

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

- Not at all hesitant Not too hesitant Not sure
 Somewhat hesitant Very hesitant

18. I trust the information I receive about shots.

- Strongly agree Agree Not sure Disagree Strongly disagree

19. I am able to openly discuss my concerns about shots with my child's doctor.

- Strongly agree Agree Not sure Disagree Strongly disagree

20. All things considered, how much do you trust your child's doctor? (circle your choice)

Do not trust at all										Trust completely										
(circle the number that represents your choice)																				
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

21. What are the three most important sources of information that have helped you to make decisions about your youngest child's vaccinations? (check up to three items from the list)

- My child's primary doctor
 Other health care providers
 Family members
 Friends
 The child's other parent
 The Internet
 Newspapers and magazines
 Books
 Television

- The American Academy of Pediatrics
 - The Centers for Disease Control and Prevention (CDC)
 - Other (please describe)
-

The following questions will be used to help us describe the general characteristics of study participants:

22. Your Age: _____

23. Gender: ___ Female ___ Male

24. Race: ___ Caucasian
 ___ Black
 ___ Asian/Pacific Islander
 ___ American Indian/ Alaska Native

25. Ethnicity: ___ Hispanic ___ Non-Hispanic

26. What is your highest educational level?

- Less than high school graduation
- High School Diploma
- Associate Degree, Technical school diploma or some college
- Bachelors' Degree
- Graduate Degree

27. What is your approximate annual household income?

- Less than \$30,000
- \$30,000 to \$49,999
- \$50,000 to \$69,999
- \$70,000 or more

APPENDIX C: FOCUS GROUP DISCUSSION GUIDE

Opening Question: (Ice breaker)

When you think of immunizations, what are some of the things that come to mind right away? Let's have each person just say a word or two, the first thought that comes to your mind.

Thanks. Now I would like to turn our conversation to the topic that we are here to discuss tonight – childhood immunizations.

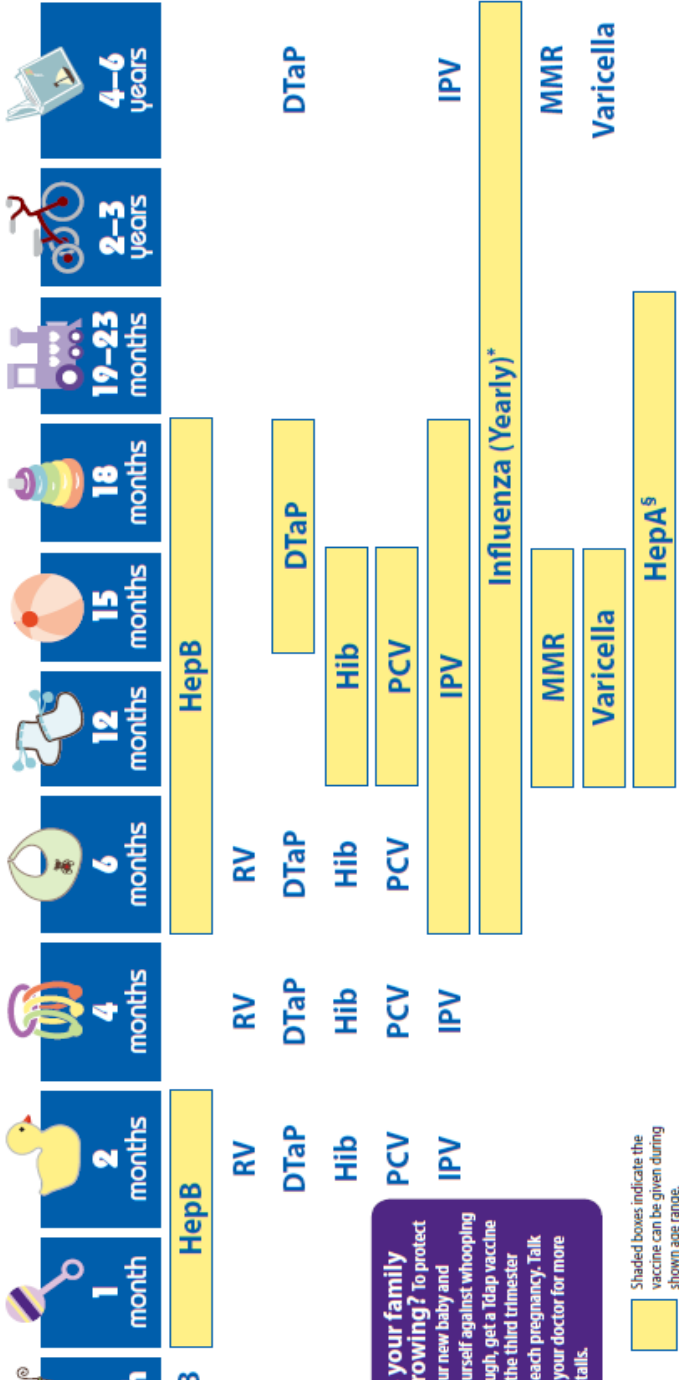
Key Questions:

1. First, how effective do you think that the recommended vaccines generally are at preventing childhood diseases (such as polio, measles, mumps, chicken pox, or whooping cough)?
 - a. Are there specific vaccines that you think are less effective than others?
 - b. Why do you think they are not effective?
2. How important do you think that the recommended childhood immunizations are for protecting your child's health?
3. How important do you think it is that your child be immunized to help protect the health of other children?
4. How safe do you think childhood immunizations are?
 - a. What adverse outcomes are you concerned about?
 - b. Are there some vaccines that are more worrisome than others? Which ones?
 - c. Do you think that the possible dangers from immunizations outweigh the risks from a child getting a vaccine-preventable disease?
5. How comfortable do you feel about discussing your questions or concerns about immunization with your child's doctor?
 - a. What has been the doctor's response? Or, if you haven't talked to the doctor, how do you *think* he/she would respond?
 - b. Have you talked with the nurses in the doctors' office, or other healthcare providers about your concerns?
 - c. How satisfied were you with the answers that your healthcare provider offered?
6. What sources of information do you trust when you have questions about vaccinating your child?
 - a. How do you know which to believe?
 - b. What do you do when different sources of information disagree?
 - c. How much do you trust what your child's doctor says?
 - d. Are there other informational resources that you wish you had access to?
7. What are your biggest unanswered questions or concerns about childhood immunization?

END OF INTERVIEW

APPENDIX D: CDC - RECOMMENDED IMMUNIZATION SCHEDULE

4 Recommended Immunizations for Children from Birth Through 6 Years Old



FOOTNOTES: * Two doses given at least four weeks apart are recommended for children aged 6 months through 8 years of age who are getting a flu vaccine for the first time and for some other children in this age group.
 † Two doses of HepA vaccine are needed for lasting protection. The first dose of HepA vaccine should be given between 12 months and 23 months of age. The second dose should be given 6 to 18 months later. HepA vaccination may be given to any child 12 months and older to protect against HepA. Children and adolescents who did not receive the HepA vaccine and are at high-risk, should be vaccinated against HepA.
 If your child has any medical conditions that put him at risk for infection or is traveling outside the United States, talk to your child's doctor about additional vaccines that he may need.

For more information, call toll free 1-800-232-4636 or visit www.cdc.gov/vaccines

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

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