Parental and Provider Attitudes, Practices, and Beliefs about Childhood Immunizations in Kansas

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EXECUTIVE SUMMARY

Children who are not fully immunized until they enter school are at risk for potentially serious, preventable diseases during their preschool years and may contribute to the spread of these diseases among susceptible adults. Vaccination coverage levels of 90 percent are generally sufficient to prevent circulation of viruses and bacteria-causing disease. Historically, immunization coverage rates for Kansas children have been lower than 90 percent. Increasing both the immunization rate and the timeliness of immunizations will require an understanding of the many factors that influence the behavior of both parents and providers.

A qualitative, semi-structured interview method was applied to elicit comprehensive responses and salient themes from three relevant populations: private provider clinics, local health departments, and parents of children aged 0–35 months old. The sample parent population was selected from patients of the private provider clinics included in the study and from the local health department clinics in the same counties. Recruitment resulted in 39 providers (26 private providers and 13 local health departments) and 55 parents.

Parents and providers identified different barriers to immunization. Providers cited parental resistance as a significant barrier, while parents noted their need for more education and follow-up activities from their providers. The most common barrier reported by parents was scheduling-related issues. Cost and parent/patient burden were recognized by both providers and parents as important barriers to the timely immunization of Kansas children.

Common themes about the childhood immunization process in Kansas emerged. Good parent information, education and follow-up were identified as the most significant facilitating factors by both providers and parents. However, providers preferred less interactive methods such as reminder postcards and public campaigns while parents preferred more personalized approaches like direct education. In addition, many providers expressed the belief that their current involvement in parent education and follow-up is adequate, while parents stated that they would like providers to step up their efforts in these areas. It appears that parental needs for education and follow-up are currently not being met despite provider efforts.

INTRODUCTION

Immunizing children against infectious disease is an essential mission of both state and national public health systems. During the 20th century the United States has seen the incidence of measles, pertussis, and diphtheria fall by more than 98 percent. This is due primarily to the use of vaccines that immunize children against these illnesses. But many children are still not adequately vaccinated, and levels of some disease can be lowered further (http://www.cdc.gov/nis). Maintaining high levels of immunizations also is important to prevent the resurgence of diseases now rare.

Children who are not fully immunized for their age are at risk for potentially serious, preventable diseases during their preschool years and may contribute to the spread of these diseases among susceptible children and adults. Maintenance of high vaccination coverage levels in early childhood is the best way to prevent the spread of vaccine preventable diseases (VPD). Vaccination coverage levels of 90 percent are generally sufficient to prevent circulation of viruses and bacteria-causing VPD (http://www.mathepi.com/maindir/herd.html).

In 1996, the national Childhood Immunization Initiative set a goal of 90 percent for vaccination rates of two-year-olds for measles, mumps, rubella, diphtheria, tetanus, pertussis, polio, and *Haemophilus influenzae* type b. Data from the 2006–2007 National Immunization Survey (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5634a2.htm) indicate that this goal was achieved nationally for individual vaccines, with the exception of the diphtheria-tetanus-pertussis combination (85 percent). However, rates were only 77.5 percent for the entire series of recommended vaccinations (Table 1) and substantial local and regional disparities continue to exist. Clearly, progress is needed to fully achieve herd immunity and disease eradication.

Table 1. **Recommended Childhood Vaccinations**

4 or more doses of any diphtheria, tetanus toxoids, and pertussis vaccines (DTaP/DTP/DT)
3 or more doses of any poliovirus vaccine
1 or more doses of measles-mumps-rubella vaccine
3 or more doses of *Haemophilus influenzae* type b (Hib) vaccine
3 or more doses of hepatitis B vaccine;
1 or more doses of varicella at or after child's first birthday

Historically, immunization coverage rates for Kansas children have been lower than the 90 percent goal for some vaccines and have fluctuated over time. Most recently, for the 2006–2007 survey years, Kansas achieved greater than 90 percent vaccination rates for polio, measles-mumps-rubella, and *Haemophilus influenzae* type b, but only 86 percent for diphtheria-tetanus-pertussis and 72 percent for the entire series of recommended vaccinations. These coverage rates ranked Kansas 43rd in the nation in the most recent National Immunization Survey (NIS) for the entire recommended series of vaccinations — the 4:3:1:3:3:1 series. The state ranked 35th for the 4:3:1:3:3 series, down from 12th in 2005. Increasing the immunization rate and the timeliness of immunizations requires an understanding of both modifying and moderating influences that can affect how providers and parents decide if and when to immunize a child.

In 2003, a unique group of stakeholders came together in Kansas with one goal — protect every Kansas child from vaccine preventable diseases. As part of this effort, the Kansas Health Institute conducted a qualitative study among health care providers, local health departments, and parents of children 0–35 months of age to elicit their beliefs and attitudes related to the delivery of timely immunizations. Beliefs and attitudes are important constructs in understanding behavior from the theoretical perspectives of the Health Belief Model (Stretcher and Rosenstock, 1997), Social Cognitive Theory (Bandura, 1986), and the Theory of Planned Behavior (Ajzen, 1991). An open-ended, qualitative approach that fully captures the language, perceptions, meanings, and beliefs of respondents is an appropriate method to elicit relevant beliefs from a target population. This report describes the study findings and proposes possible intervention opportunities suggested by the results.

METHODS

SAMPLING

The sampling frame for this study resulted from a previous study of Kansas licensed family physicians, general practitioners and pediatricians identified through the Board of Healing Arts. A random sample of three private health care providers was selected from each service/size stratum (Table 2), along with the local health department located in the same county as the private provider. Another random sample of three parents of age-eligible patients from each private provider and each local health department also was targeted for selection. The final sample population consisted of 27 private providers, 27 local health departments and 162 parents.

Table 2. **Sampling Frame for Private Providers**

Immunization Services Offered	Clinic Size
NONE (Clinics that give NO immunizations)	Large Clinics (≥10 physicians) Intermediate Clinics (2–9 physicians) Solo Practices (1 physician)
PARTIAL (Clinics that give immunizations to SOME of their clients)	Large Clinics (≥10 physicians) Intermediate Clinics (2–9 physicians) Solo Practices (1 physician)
ALL (Clinics that give immunizations to ALL of their clients)	Large Clinics (≥10 physicians) Intermediate Clinics (2–9 physicians) Solo Practices (1 physician)

RECRUITMENT

All clinics in the sampling frame were contacted by mail to inform them of the study and of their potential selection as a participant. Clinics were assigned unique identification numbers and randomized by strata (i.e., clinic size and level of immunization services offered). The clinics were contacted by telephone in this randomized order and invited to participate in the study. To participate, clinics were required to support the parent recruitment protocol. If a clinic declined to participate, the recruiter contacted the next clinic on the randomized list until at least three clinics in each stratum were recruited. When a clinic agreed to participate, the local health department in the same county was called and also invited to participate.

During the recruitment telephone call, an appointment for data collection was made and the parent recruitment protocol was explained. Clinics and local health departments were instructed to randomize a list of their age-eligible patients and select the first 25 patient families. Prior to the data collection interview, the clinics and local heath departments prepared mailing labels or a mailing list with the selected families' names and addresses. After the interview, providers were given parent recruitment letters, parent response cards, and postage paid envelopes to send to parents. As parent response cards were returned to the clinic or the local health department, they were forwarded to the Kansas Health Institute and assigned unique identification numbers. Recruiters contacted parents by telephone and those that agreed to participate were interviewed on the telephone at that time or at another mutually agreeable time.

Informed consent (Appendix A) was obtained from providers in writing and copies were provided to each clinic or local health department. Informed consent from parents (Appendix B) was obtained verbally at the time of the telephone interview and a hard copy of the informed consent document was mailed to each parent. All identifying information was kept in locked cabinets and password protected computer files. After tape transcription, identifying information was destroyed.

As an incentive for their participation, clinics and local health departments were given their choice of the American Academy of Pediatrics' Red Book or a $100 gift certificate to Amazon.com for completing the interview and supporting the parent recruitment protocol. In addition, some clinics opted to conduct the interview during a breakfast or lunch session hosted by the project. Parents were given a $20 gift certificate to Wal-Mart for completing the parent interview.

DATA COLLECTION

Provider Interviews

A semi-structured interview (Appendices C and D) was conducted with designated provider representatives by an interviewer trained in qualitative interviewing techniques and in conducting the specific interview. Interviews were tape recorded. Through specific probes, barriers (external and internal) to providing immunizations and facilitating factors for timely

immunization were explored. Providers were asked to provide a rationale for the differences in clinic practices with regard to immunization practices. Provider attitudes and beliefs about immunization practices in Kansas and the potential impact of immunization system restructuring on the clinic/local health department's practice were also explored. Interviews were approximately one to 1.5 hours in length.

Parent Interviews

Parent interviews (Appendix E) were semi-structured and conducted by interviewers trained in qualitative interviewing techniques. The interview was recorded with a telephone recording device on tapes labeled with the patient's identification number. The interview included an assessment of the child's immunization status by parent report, parent satisfaction with the immunization process, barriers and facilitating factors to timely immunization, and suggestions for system improvement. Parent interviews were 30–45 minutes in length.

DATA ANALYSIS

Audio tapes of interviews were transcribed and prepared for analysis by a professional transcription service. Data were analyzed for recurrent content themes using QSR N6 qualitative analysis software. Interview comments were first categorized as Barriers or Facilitators to complete a timely immunization and then coded in thematic nodes. The nodes were rank ordered by affect, intensity, and frequency. The five highest ranking nodes were selected to represent the salient themes (Ajzen, 1991; Ajzen & Fishbein, 1980) except when a considerable gap in frequency occurred. In these cases, fewer than five salient themes were identified. Results are reported as the frequency of interviews containing comments coded in the thematic nodes.

RESULTS

SAMPLE

Recruitment efforts resulted in the interviews of 39 providers (26 private providers and 13 local health departments) and 55 parents, 44 percent of the sample population. Table 3 shows the distribution by clinic size and level of immunization services of private providers and parents in their practices. Local health departments and their clients were selected based on the location (i.e., county) of the private providers' clinics. The geographic distribution by county of the participants is shown in Figure 1. The low population density of the northwest quadrant of the state accounts for its exclusion by the random sampling procedure.

QUALITATIVE FINDINGS

This report provides results to the open-ended interview questions pertaining to barriers and facilitators of timely and complete immunization of Kansas children. Analysis of themes stratified by respondent category is shown in Table 4. Table 5 provides illustrative quotations portraying the domains of each theme.

Table 3. **Parents and Providers Sample**

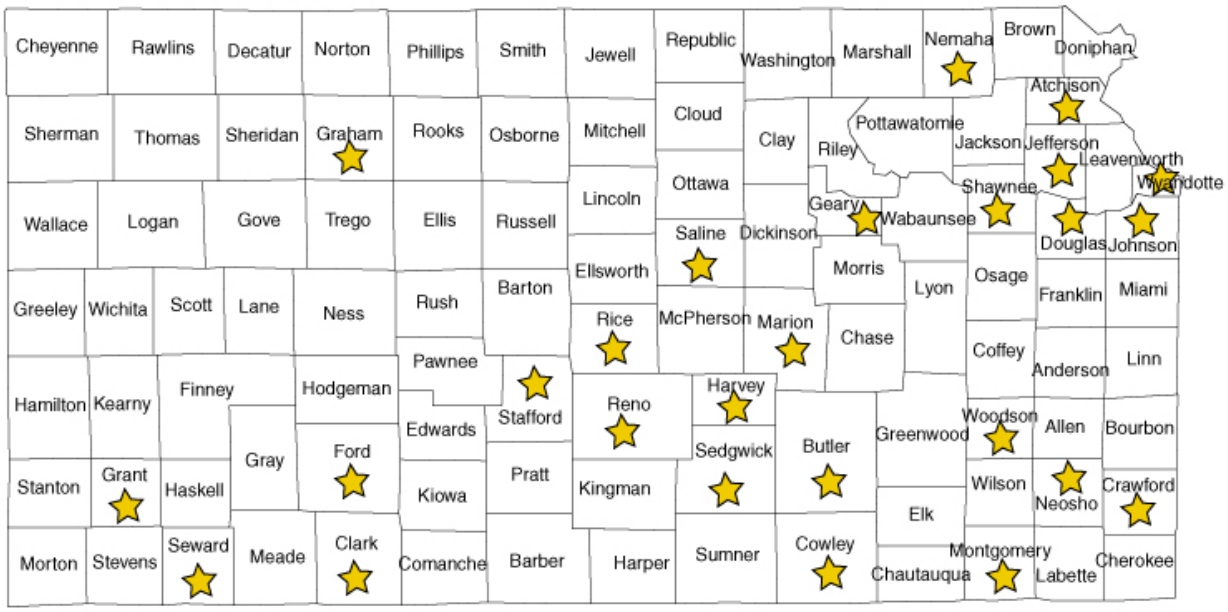
Immunization Services Offered	Clinic Size	Private Provider Interviews	Private Provider Parent Interviews
NONE (Clinics that give NO immunizations)	Large Clinics (≥ 10 physicians)	1	2
	Intermediate Clinics (2–9 physicians)	2	1
	Solo Practices (1 physician)	2	4
PARTIAL (Clinics that give immunizations to SOME of their clients)	Large Clinics (≥ 10 physicians)	2	5
	Intermediate Clinics (2–9 physicians)	5	1
	Solo Practices (1 physician)	3	7
ALL (Clinics that give immunizations to ALL of their clients)	Large Clinics (≥ 10 physicians)	1	3
	Intermediate Clinics (2–9 physicians)	5	3
	Solo Practices (1 physician)	5	4
Totals		26	30

Barriers

Providers most often cited ***cost*** as a barrier to children receiving timely immunizations in Kansas. Providers stated that cost was an issue for them and for parents. Providers reported

instances of parents choosing to delay immunizations due to out-of-pocket expenses. They also said that cost was an issue for them; specifically the cost of maintaining vaccine supplies, equipment, and financing the staff positions necessary for providing immunization services. For providers, this was the primary reason immunizations services were not offered to their patients. While parents agreed that cost was a factor for not immunizing children on time, it ranked as their third concern behind *scheduling* and *parent/patient burden*. When speaking about cost-related issues, parents rarely reported that they could not afford vaccinations, but believed it could be a factor for other parents, especially low-income or uninsured families.

Figure 1. **Geographic Distribution of Participants**



Parents were most concerned about barriers related to ***scheduling***. Many cited inconvenient clinic hours for working parents, the need to reschedule appointments due to providers' inadequate vaccine supply, difficulty rescheduling missed appointments, inconvenient provider locations, and restrictions that require appointments for immunizations and well child visits to be separately scheduled.

Parent/patient burden ranked second for both parents and providers as a barrier to completing timely immunizations. Attitudes and beliefs related to this theme included the overall number of injections, the number of injections given during any one visit (especially if the child

was behind schedule or previous inoculations could not be verified), the physical pain experienced by the child, and the emotional pain experienced by the parent (including the shame of being behind schedule). Parents also reported long wait times at clinics, paperwork burdens related to insurance verification/reimbursement, and lack of support from providers who were insensitive to children's pain reactions. Interestingly, some providers cited the latter as a reason they chose not to provide immunization services. They did not want their patients to associate pain with visits to the clinic.

The third and fourth ranking barriers to immunization reported by providers were ***population characteristics*** and ***parental resistance***, respectively. The content of these themes differed slightly. Population characteristics were most often described as features inherent to the specific local population served by the provider and sometimes not amenable to provider intervention. These characteristics included population transiency, language barriers, socio-economic status, ethnicity, and a general attitude of noncompliance. Conversely, parental resistance was used to describe instances when parents refused to have their children immunized because they had concerns about the safety of vaccines or the belief that vaccinations are no longer necessary. Providers believed they had some ability to break down this barrier through persistent parent education.

Parents agreed with providers about their need for education, ranking ***lack of education*** fourth as a barrier to timely immunization. However, parents' description of this barrier may reflect an important perceptual difference between parents and providers. Parents expressed confusion and concern that providers did not take the time to explain the immunization schedule, the need for all the immunizations, and what parents should expect during and after the immunization. Parents believed that it was the providers' responsibility to deliver this information in advance of the need for immunizations, preferably at the hospital after the child's birth. Parents did not believe that they were generally uncooperative or noncompliant. However, providers most often saw parent education as a necessary intervention to avert parental refusal of vaccinations, rather than to prevent inaction due to parental confusion or ignorance.

And finally, parents reported ***lack of follow-up*** as the fifth barrier to immunization. Some parents reported they never got information about immunizations from their private health care

provider and many reported that they "figured it out" themselves. While most parents reported that they had received some kind of reminder, they frequently believed it was not sufficient given the many demands of family life today.

FACILITATORS

Parent education is the most effective tool — facilitator — at the disposal of groups seeking to improve the immunization rate, as pointed out by over half of the providers. Interestingly, parents and providers disagree on how effective this tool is being utilized. Providers believe they are doing a good job. Parents, on the other hand, believe that providers could be doing a much better job. A closer examination of the types of education used by providers offers a clue to the disparity. Providers most often described indirect education such as printed materials (i.e., vaccine information sheets, handbooks, and posters) or electronic media campaigns as preferred modalities of parent education. However, parents stressed that direct conversations with providers were how they preferred to receive education.

Providers also ranked ***follow-up*** high (second) as a chief contributor to timely immunizations. Most providers used some type of reminder system for their patients, primarily the reminder postcards supplied by the state. However, those providers reporting the highest coverage rates almost always made reminder telephone calls and in some instances made home visits. The most successful providers compared their procedures to those used by dentists and believed that their patients were satisfied with these comprehensive efforts. One provider was in the process of piloting a parental message texting reminder system.

Public campaigns, especially media campaigns, was ranked by providers as the third most effective immunization facilitator. Campaigns with incentives, such as *"Immunize and Win a Prize,*" were believed to be the most effective. Providers who mentioned this facilitator also believed that more sustained efforts to reach parents in this manner would likely further increase complete and timely immunization across the state. Some providers suggested that content of these campaigns should also focus on education about the diseases being prevented. These providers shared a common belief that the success of immunizations in controlling diseases had fostered a careless attitude among parents that needed to be countered.

Table 4. **Provider and Parent Comparisons**

Barriers to Immunizations				Facilitators of Immunizations			
Providers		**Parents**		**Providers**		**Parents**	
Cost	33	Scheduling	24	Parent education	34	Follow-up	43
Parent/patient burden	23	Parent/patient burden	19	Follow-up	26	Parent education	35
Population characteristics	22	Cost	18	Public campaigns	25	Immunization delivery	20
Parental resistance	20	Lack of education	16	Schools/ day cares	23	Immunization schedule	20
		Lack of follow-up	13	Immunization delivery	18	Well child visits/single location	18
Inconsistent practices		Insurance		Immunization schedule		WIC	
Logistics		Parental resistance		State actions		Prescheduling	
Family schedules		Transportation		Registry		Medical home	
Lack of education		Inconsistent practices		Incentives		Public campaigns	
Lack of provider awareness		Language		Provider networks		Insurance	
Staffing				Universal coverage		Vaccine availability	
Regulations				Provider experience		Legal mandates	
Access				Access		Immunization registry	
Lack of follow-up						Incentives	
Vaccine availability							
Transportation							

Note: Frequencies represent number of interviews. Themes above dotted line represent salient beliefs.

Providers said that ***schools/day cares*** could play a role in improving immunization rates. The combination of a legal requirement for enrollment along with the mutual cooperation between school nurses and providers was often cited as an effective approach for motivating parents to ensure that their children were fully immunized. Many providers believed that schools and day cares were underutilized as venues for immunization delivery. Some providers believed that school nurses should be able to administer immunizations. The possibility of conducting immunization clinics at school sites was frequently discussed, often with references to the success of the polio vaccination drives of the late 1950's.

And finally, providers believed that the mode of ***immunization delivery*** itself could be a powerful immunization facilitator. This theme included both comments related to delivery venue and to vaccine formulas. Echoing the attitudes expressed by parents, providers suggested that extended hours and more accessible locations for providing immunizations would increase immunization rates statewide. Providers also reported that parents were more satisfied with combination vaccines because they reduced the number of shots required to achieve full immunity. Universally, providers expressed the need for state leadership to increase both access and delivery options, perceiving this issue as too broad for any one provider to undertake.

Parents agreed with providers that ***follow-up*** was crucial to timely and complete immunizations, and ranked it as the most important facilitator for them. Follow-up methods that parents especially appreciated included eye-catching postcards and telephone calls. Parents also wanted follow-up to begin at birth before leaving the hospital so that they would know what to expect. Several parents mentioned other forms of follow-up they would like to have, such as refrigerator magnets with the immunization schedule and e-mail contact. Parents were clear that they rely heavily on providers for guidance and direction about timing of immunizations. Some parents expressed irritation that providers did not do a better job of keeping them informed about the timing of immunizations, suggesting that providers are at fault when children are not immunized on time because they do not schedule immunization follow-up appointments at well child visits or tell parents when to return. This was especially true for those parents who experienced delays in immunizations because their provider opted not to give vaccinations during visits scheduled for other purposes.

Parent education was scored by parents as the second most effective means of achieving higher immunization rates. But again, parents stressed that they preferred to receive the information in face-to-face visits with their providers. Several parents expressed satisfaction that their provider answered their questions in a supportive and nonjudgmental manner. Others noted that their counties had a visiting nurse program for first time mothers that included distribution of an information packet containing the immunization schedule as well as other useful and practical educational material. Parents especially wanted to know which immunizations were required and which were optional so that they could make more informed decision for their children. Repeatedly, parents stressed that providers should not assume that parents know or

understand why immunizations are important. Many parents believed that providers have a duty to disclose information about the benefits and risks of immunizations but often failed to do so.

The third highest ranking facilitator for parents was ***immunization delivery***. Parents appreciated providers who minimized their wait times and showed concern for the child's pain experience. Administering immunizations quickly with two clinic staff, if necessary, was viewed favorably by parents when four or more shots were required. Parents wanted to see more use of combination vaccines and novel delivery methods such as nasal sprays or oral formulas if possible.

Parents ranked ***immunization schedule*** as the fourth highest facilitator of immunizations. Parents believed that a consistent schedule would improve immunization rates as long as providers adhered to it closely. Parents were confused when private providers did not offer immunizations or followed different immunization schedules than those recommended by the state. Parents were split in their attitudes toward the current schedule. While some parents did not express concerns about the current schedule, others said they preferred a schedule that required fewer injections per visit. However, parents generally agreed that a well-publicized schedule was essential to ensuring that all children were fully protected against vaccine preventable diseases.

Well child visits and ***single immunization provider*** tied as the fifth highest facilitator cited by parents. These two themes were related to each other through parent convenience. Receiving immunizations in the context of a well child visit was viewed as logical and appropriate by parents. Parents indicated that being able to combine the two procedures made it easier for them to adhere to the immunization schedule. Parents also expressed a preference for receiving their children's immunizations from a single provider, regardless of whether it is a private clinic or a local health department.

Unlike providers, parents did not mention the use of ***Incentives*** (such as *"Immunize and Win a Prize"*) as an important factor in their efforts to immunize their children timely.

CONCLUSIONS

From the information collected through qualitative interviews of Kansas parents and health care providers, we identified recurrent issues which, if addressed, could strengthen the immunization delivery system. Both parents and providers recognize the pivotal role of patient follow-up and education to timely and complete immunization of Kansas children. However, parental needs for follow-up and education are currently not being fully met despite provider efforts. Cost also represents a barrier in several ways. Both providers and parents are concerned about immunization costs for underinsured patients. And providers emphasized that the cost of administering immunizations also stood as a barrier to achieving higher rates.

The development of a more complete and accessible immunization registry can be an essential step to address many of the parents' and providers' concerns. Such a system would allow parents to monitor the immunization status of their children and give providers an effective tool for tracking children as they age or move. The system needs to be secure and sufficiently flexible to serve the needs of both parents and providers. Registering children at birth and providing parents and providers with secure access to the registry would enhance the ability of all those concerned with the child's health to track, monitor and receive information related to the child's immunizations. Strengthening the linkage between private providers and LHDs through the registry also could represent an important element to assure that children referred for immunizations from one site to another receive timely vaccinations.

Achieving a goal of complete and timely immunization of Kansas children will require greater participation by private providers. This is unlikely unless cost issues are actively managed. Cost concerns of private providers (and of some local health departments) include both the cost of the immunizations and the costs associated with administrative requirements. A streamlined state process for bulk vaccine purchasing that passes discounts to providers and reduces providers' financial risk could alleviate some of the cost barriers reported by providers. In addition, a flexible immunization registry as discussed in this report could simplify administrative procedures thereby reducing costs to providers.

Providers are particularly concerned about costs associated with providing immunizations to their underinsured patients. State-level action to increase insurance coverage and reimbursement levels for required immunizations is viewed favorably by both parents and providers. The current financing system pressures some families to trade the benefits of immunizations for more immediate financial needs.

Efforts to reduce parent/patient burden by emphasizing well child care that allows for easier implementation of the recommended immunization schedule will increase parent satisfaction and support providers' goals of holistic health care. Parents often expressed support for the concept of one medical home for all the health care and prevention needs of their children. Parents also have a high consideration for education and follow-up received directly from their provider. Encouraging providers to administer immunizations to children when they come to the office for a well child visit or for other reasons would streamline the process and could improve timeliness of immunizations. State campaigns can encourage immunizations in the context of a well child visit, thus promoting two goals of providers and increasing parental cooperation. The burden on parents and children could be further decreased through the increased use of multi-antigen combination vaccines whenever possible.

Increased and sustained educational campaigns coupled with incentive promotions could be effective methods for boosting immunization rates. Both parents and providers believe that more efforts directed to statewide educational campaigns are needed to maintain awareness of the importance and need for childhood immunizations. Satisfaction and positive outcomes with previous state campaigns inspired confidence in the state's abilities to reach and motivate parents. Providers especially appreciated accompanying campaign materials and incentives that established a perceptual link between the provider and the state for parents. Interestingly, providers considered the role of incentives and rewards for parents (such as the *"Immunize and Win a Prize"* program) more important than parents reported, although some parents viewed the incentives as a value-added motivation for immunizing their children on time.

In conclusion, this study highlights some barriers among providers and parents that can be addressed through a combination of interventions including financial, educational and

organizational components. Providers and parents both appear to be committed to vaccinating children on time, but in some cases they face obstacles that prevent them from achieving this goal. Parents rely on their doctors as credible sources of information and education and, in most cases, prefer to have their children immunized at their doctor's office. Both private providers and local health departments recognize the central role that local health departments play in assuring that all children are immunized at the right age, either by directly providing vaccinations or by assisting private providers to assure timely immunizations in the children's medical homes. Ultimately, progress in this area will depend upon the local implementation of well-conceived, coordinated strategies by private providers, local health departments and parents with support from the state.

Table 5. **Examples of Attitudes and Beliefs from Major Themes**

BARRIERS	FACILITATORS
Cost	**Well Child Visit**
Private Provider: "Because I think parents want to do the right thing for their children. There's some that can't afford it, that might be a time that they would just say 'I don't have ten bucks.'"	*Parent:* "It's convenient. I do it right there when she has her well child checkup."
Parent: "You're like, 'Oh my gosh, we're running low on money for diapers, and food, and whatever. How am I going to come up with $100 or whatever to go get shots?'"	*Parent:* "From other friends and parents I've talked to, I think having to go to another place to do it and not being able to do it when you have the well child check makes it a little more difficult."
Scheduling	**Follow-up**
Parent: "There are a lot of people who work a nine-to-five job. They don't have time. After five, they're closed. On top of that, they close in the middle of the day."	*Private Provider:* "I think personally we have a pretty good system. Our particular office we send out postcards or reminder cards…"
Parent: "I understand that's hard for them [the health department], but it would be nice if they had more days that they offered shots."	*Private Provider:* "So some type of flag system and then being able to have the staff to make those calls and to remind them. But reminders I think would be the biggest thing."
Parent: "And I say that God is what makes it easier because, totally, if I were working … depending on where you work and how flexible they are with you, I would assume that to some parents it is quite difficult."	*Parent:* "Besides just reminding me verbally, which he does already, I guess maybe he could send something in the mail to remind me too. We're becoming such a computer generation. We could get an e-mail…[text] message at work for those busy parents…"

Table 5 (continued). **Examples of Attitudes and Beliefs from Major Themes**

BARRIERS	FACILITATORS
Parent/Patient Burden *LHD:* "I think it's getting a little overkill on those. A lot of the immunizations that are coming out…you know there is just so many anymore. Parents kind of wonder when it is going to be enough." *Parent:* "I didn't like how many one year shots she got." *Private Provider:* "Had a lot of complaints about too many, especially chicken pox. 'We'll just wait. Maybe he'll catch it.'" *Parent:* "The only thing I would say I don't like is from the time that the doctor walks out to the time the nurse actually gets the stuff is generally like half an hour. Like this last time I had to wait like an hour for her shots."	**Immunization Delivery** *Parent:* "I do wish that they could combine shots. I know they're kind of — some of them are combined and stuff — but I don't like it when they have to get like four or five shots at a time." *Parent:* "Maybe something that might be less painful for the child, but I don't know if the potency diminishes if you do it orally or if there is such a thing. I know some vaccines I've read somewhere that some could be administered orally." *Parent:* "They just did it quickly. It wasn't wide spread. They didn't give him one and then tell me about it and then give him another one. They tried to do it as quickly as they could, so it could just be all over all together."
Population Characteristics *Private Provider:* "Usually… I've seen, the people that usually have…seem to have a problem with it is people that are not really…I would say not really educated in that way." *LHD:* "You know, the dad has them now because they used to live with the mother in Georgia, and the mother got put in jail."	**Public Campaigns** *Private Provider:* "…Maybe more advertising….some type of campaign…show a mom what a polio patient looks like. Show a mom whooping cough in a six week old." *Private Provider:* "I don't know if you could host or sponsor immunization days. I think they do that at the health department."
Lack of Follow-up *Parent:* "When I took my son to the doctor for his shots, I never heard back when the next ones were due. They didn't know if I'd had them done or not." *Parent:* "They didn't care I guess." *Parent:* "No. I didn't get anything in the mail from my pediatrician that mentioned anything as far as her shots." *Parent:* "You know they never gave me a shot schedule."	**Legal Mandates** *Private Provider:* "…we see kids everyday that have not had anything [immunizations] and they are in school and they are going to get kicked out…that's not a rare exception. It's more of a semi-norm." *LHD:* "…if the provider is knowingly not following the schedule, and there's no real reason other than their preference…can something be done? I mean… a penalty or something that encourages them to… follow that schedule?" *Private Provider:* "…but even if access to your Medicaid status depends on whether you've kept compliant with your immunizations."

Table 5 (continued). **Examples of Attitudes and Beliefs from Major Themes**

BARRIERS	FACILITATORS
Parental Resistance *Private Provider:* "The reasoning is autism. They don't want their children to get autism." *Private Provider:* "Parents…there's lots of young parents now that are just kids themselves … they don't like to see their babies cry. They can't stand shots themselves. They don't want their babies getting shots."	**Insurance** *Private Provider:* "We would have to bill a lot more insurance companies…that would be a nightmare... for my billing clerk but it would be wonderful to get immunizations covered." *Private Provider:* "I don't think it would be requiring your patients to have insurance. I think it would be requiring that insurance pay for all immunizations."
Lack of Parent Education *Parent:* "…'No, I don't think so. He hasn't had a tetanus shot.' And then somebody said, "Well, the tetanus shot is the DTaP or whatever." And you know, we didn't even know that our kid had had their tetanus shot." *Parent:* "Lack of knowledge. I think on those happy little pink cards that you guys all distribute — I think that it would be wise or helpful for parents if you could print on there the ages that these children receive those particular shots."	**Immunization Schedule** *Parent:* "I don't find it hard to follow. It's easier when they're little just because they are so close together, and you do have to get checkups, so you do that." *Parent:* "It's not like they have to have a bunch of shots at one time. They spread it out so that they're not going through tremendous pain and tremendous fevers all at once. They spread it out evenly."
	Education *Private Provider:* "So we try our very best to support them, educate them, encourage them to come back…" *Private Provider:* "We also give a handout book that is more general to the parents. It talks about immunizations…This facility actually took this upon themselves to make up these books…" *Parent:* "I wonder if maybe they could stress a little bit more — not take it for granted that people realize how important the shots are…maybe just more education on why they should do it."

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APPENDIX A: PROVIDER INFORMED CONSENT

RESEARCH CONSENT/AUTHORIZATION FORM

KDHE INSTITUTION REVIEW BOARD STUDY # __

STUDY TITLE:

PARENTAL AND PROVIDER ATTITUDES, PRACTICES, AND BELIEFS ABOUT CHILDHOOD IMMUNIZATIONS IN KANSAS

This is a qualitative interview (a type of research study). Only those participants who choose to take part are interviewed. Please take your time to make your decision. You have the right to ask questions and/or receive further information before making your decision.

PRINCIPAL INVESTIGATOR: Gianfranco Pezzino, M.D., M.P.H.
STUDY DIRECTOR: Candace Ayars, Ph.D.
PHONE NUMBER: 785-233-5443

You are being asked to take part in this research study because you have been identified through the Kansas Board of Healing Arts as a family practice clinic, a general practice clinic, a pediatric clinic, or a local health department operating in the state of Kansas.

This form serves two purposes: 1) It provides information about the research study and the possible benefits and risks involved; 2) It describes the protected health information (PHI) that will be obtained during the research study — how the PHI will be used and with whom it will be shared.

This study is being sponsored by a grant from the Kansas Health Foundation. Portions of Dr. Pezzino's, Dr. Ayars' and the study research team's salaries are being paid by this grant.

WHY IS THIS STUDY BEING DONE?

The purpose of this research study is to find out about the experiences, attitudes, and beliefs that parents, doctors, and nurses have about children's immunizations in Kansas.

This research study is being done because many Kansas children do not get their immunizations on time and the reasons for this are unknown.

How Many People Will Take Part in the Study?

About 27 private providers and 27 local health departments chosen from across the state of Kansas will take part in this research study.

What Is Involved in the Study?

If you choose to participate, a research team member will conduct an in-person interview with a supervising physician, nurse, or administrator from your clinic or health department. We will ask you questions about your opinions, practice, and experiences related to immunization services for children in Kansas, as well as your suggestions for improvement. The interview will be recorded on a tape recorder, so that the research team can have an accurate and complete record of the interview. You may choose not to have the interview recorded in which case the interviewer will take notes during the interview.

How Long Will I Be in the Study?

The interview will take about one hour, and will be scheduled at your convenience. This interview may be scheduled during breakfast or lunch if you choose. There is no expiration date for the use and disclosure of information you provide.

What Are the Risks of the Study?

The primary risk of the study is that your confidentiality could be violated and the answers to the interview questions might be overheard or read by staff not involved in the study. Every effort will be made to protect your confidentiality. None of your comments will be directly attributed to you personally or to your practice/clinic/department.

You may also feel uncomfortable with some of the questions during the interview. You may choose not to answer questions or may stop the interview at any time.

Are There Benefits to Taking Part in the Study?

If you agree to take part in this research study, there may or may not be direct benefit to you. We hope the information learned from this research study will benefit health care providers in the future and improve the delivery and timing of immunizations to children in Kansas.

You will have a choice of either a $100 gift certificate from a national book store for the purchase of office reading materials, or a copy of the most recent edition of the American Academy of Pediatrics' "Red Book". In addition, the study will pay for the food for the participants in the interview, if the interviews are scheduled at breakfast or lunch time. The findings from this study will be available to you on our website: http://www.immunizekansaskids.org.

What Other Options Are There?

You may choose not to participate in the study.

WHAT ABOUT CONFIDENTIALITY?

Efforts will be made to keep your personal, clinic, and/or health department information confidential. Your personal information may be disclosed only if required by law. The Kansas Health Institute complies with Federal Privacy Regulations that provide safeguards for privacy, security, and authorized access.

The researchers will maintain your confidentiality in the following ways:

- Interview audiotapes will be transcribed by a professional transcription service. The transcription will not contain your name or your clinic/health department's name. The audiotape of the interview will be destroyed after six years.
- The research data from the study will be identified with unique study identification numbers and will not contain the names of those who participate. Only authorized research staff will have access to the information linking your name to your study identification number.
- Published reports from the study will not identify individual patients, parents, doctors, clinics, or health departments.

Information from the research study will not be used to target you, your clinic, or your health department for marketing or sales communications.

The Kansas Health Institute research quality assurance staff and/or the Kansas Department of Health and Environment's Institutional Review Board and its support staff may review your research data for this study. This review will be administrative in nature and no PHI will be shared outside the Kansas Health Institute or the Kansas Department of Health and Environment.

The study results will be retained in your research record for data analysis or required governmental review for at least six years or until after the study is completed, whichever is longer. At that time, the research information will be destroyed or information identifying you, your clinic, or your health department will be removed from the study results at the Kansas Health Institute.

If data or information from the research study are submitted for publication in a journal or are presented at a meeting, your identity, your clinic's identity, or the identity of your health department will not be revealed.

WHAT ARE THE COSTS?

You may incur costs related to time involvement for participating in the interview. Costs for your time or the time for your staff participants are not reimbursable for participating in this research study.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Taking part in this research study is voluntary. You may choose not to be in the study or withdraw from the study at any time. You may also withdraw your authorization for us to use your data. If you decide to withdraw your data authorization, you must contact the study director, Dr. Candace Ayars, in writing at the Kansas Health Institute at the address listed below. Your decision not to participate or to withdraw from the study will not involve any penalty or loss of benefits.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

For questions about the research study contact the study director, Dr. Candace Ayars, at (785) 233-5443.

For questions about your rights as a research participant, contact Dr. Gail Hansen at the Institutional Review Board of the Kansas Department of Health and Environment (which is a group of people who review the research to protect your rights) at (785) 296-1127.

WHERE CAN I GET MORE INFORMATION?

You will get a signed copy of this form. Upon your request the study director can discuss the entire study plan with you and provide more information.

SIGNATURE

I am designated to make decisions for and/or I have authorization from my clinic/local health department and I agree to participate in this study.

_____ _____

Signature of Clinic/Local Health Department Representative Date

_____

Printed Name of Clinic/LHD Representative

_____ _____

Signature of Person Obtaining Consent Date

Kansas Health Institute
212 SW Eight Avenue, Suite 300
Topeka, Kansas 66603-3936

APPENDIX B: PARENT INFORMED CONSENT

RESEARCH CONSENT/AUTHORIZATION FORM
TELEPHONE SCRIPT
KDHE INSTITUTION REVIEW BOARD STUDY # __

[INTERVIEWER: START THE TAPE RECORDER BEFORE READING THIS DOCUMENT

RECORD: TAPE NUMBER: _____ TAPE INDEX NUMBER: _____

NAME OF PERSON INTERVIEWED: _____.

WORDS IN ITALICS AND ENCLOSED IN SQUARE BRACKETS SHOULD NOT BE READ ALOUD. THEY SERVE ONLY FOR REFERENCE PURPOSES.]

[STUDY TITLE]

THE TITLE OF THIS STUDY IS PARENTAL AND PROVIDER ATTITUDES, PRACTICES, AND BELIEFS ABOUT CHILDHOOD IMMUNIZATIONS IN KANSAS.

This is a qualitative interview (a type of research study). Only those participants who choose to take part are interviewed. Please take your time to make your decision. You have the right to ask questions and/or receive further information before making your decision.

The principal investigator of the study is Dr. Gianfranco Pezzino and the study director is Dr. Candace Ayars. You may contact them at (785) 233-5443.

You are being asked to take part in this research study because you have a child who is between 0 and 35 months old and your doctor or local health department is also participating.

This form serves two purposes: 1) It provides information about the research study and the possible benefits and risks involved; 2) It describes the protected health information (PHI) that will be obtained during the research study — how the PHI will be used and with whom it will be shared.

This study is being sponsored by a grant from the Kansas Health Foundation. Portions of the salaries of Dr. Pezzino, Dr. Ayars and the research study team are being paid by this grant.

[WHY IS THIS STUDY BEING DONE?]

The purpose of this research study is to find out about the experiences, attitudes, and beliefs that parents, doctors, and nurses have about children's immunizations (that is, shots) in Kansas.

This research study is being done because many Kansas children do not get their shots on time and the reasons for this are unknown.

[HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?]

About 200 parents from across the state of Kansas will take part in this research study.

[WHAT IS INVOLVED IN THE STUDY?]

If you choose to participate, a research team member will conduct a telephone interview with you. We will ask you questions about obtaining shots for your child. We are interested in your opinions and experiences, as well as your suggestions for improvement. The interview will be recorded on a tape recorder, so that the research team can have an accurate and complete record of the interview.

[HOW LONG WILL I BE IN THE STUDY?]

The interview will take one hour, and will be scheduled at your convenience. There is no expiration date for the use and disclosure of your protected health information.

[WHAT ARE THE RISKS OF THE STUDY?]

The primary risk of the study is that your confidentiality could be violated and the answers to the interview questions might be heard or read by unauthorized persons. Every effort will be made to protect your confidentiality.

You may also feel uncomfortable with some of the questions during the interview. You may choose not to answer questions or may stop the interview at any time.

[ARE THERE BENEFITS TO TAKING PART IN THE STUDY?]

If you agree to take part in this research study, there may or may not be direct benefit to you. We hope the information learned from this research study will benefit parents of children needing to be immunized in the future. A $20 gift certificate to Wal-mart will be sent to you for completing the interview.

[WHAT OTHER OPTIONS ARE THERE?]

You may choose not to participate in the study.

[WHAT ABOUT CONFIDENTIALITY?]

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Federal Privacy Regulations provide safeguards for privacy, security, and authorized access.

The researchers will maintain your confidentiality in the following ways:

- Interview audiotapes will be transcribed by a professional transcription service. The transcription will not contain your name, your child's name, your doctor's name or the name of your local health department. After transcription, the audiotape of the interview will be destroyed.
- The research records from the study will not contain the names of those who participate.
- Published reports from the study will not identify individual patients, parents, doctors, or clinics.
- We will not inform your child's doctor or local health department about your participation.

Information from the research study will not be used to target you for marketing or sales communications.

The Kansas Health Institute research quality assurance staff and/or the Kansas Department of Health and Environment's Institutional Review Board and its support staff may review your research data for this study. This review will be administrative in nature and no PHI will be sent outside the Kansas Health Institute or the Kansas Department of Health and Environment.

The study results will be retained in your research record for data analysis or required governmental review for at least six years or until after the study is completed, whichever is longer. At that time, the research information will be destroyed or information identifying you will be removed from the study results at the Kansas Health Institute.

If data or information from the research study are submitted for publication in a journal or are presented at a meeting, your identity as a research participant will not be revealed.

[WHAT ARE THE COSTS?]

There are no costs to you for participating in this research study.

[WHAT ARE MY RIGHTS AS A PARTICIPANT?]

Taking part in this research study is voluntary. You may choose not to be in the study or withdraw from the study at any time. You may also withdraw your authorization for us to use your data. We ask that if you decide to withdraw your data authorization, that you contact the study director, Dr. Candace Ayars, in writing at the Kansas Health Institute.

Your decision not to participate or to withdraw from the study will not involve any penalty or loss of benefits. It will not affect your access to health care at your doctor's office or local health department.

[WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?]

For questions about the research study contact the study director, Dr. Candace Ayars, at (785) 233-5443.

For questions about your rights as a research participant, contact Dr. Gail Hansen at the Institutional Review Board of the Kansas Department of Health and Environment (which is a group of people who review the research to protect your rights) at (785) 296-1127.

[WHERE CAN I GET MORE INFORMATION?]

You will get a signed copy of this form. Upon your request the study director can discuss the entire study plan with you and provide more information.

SIGNATURE (TELEPHONE CONSENT)

Do you understand the information about this study?
□ yes □ no

Do you have any other questions?
□ yes □ no

Do you agree to participate?
□ yes □ no

May I have your mailing address for the purpose of sending you a copy of what I have just read to you?

[Interviewer: Note participant name and mailing address on <u>participant's copy only</u> of paper consent form.]

_____ _____
Signature of Person Obtaining Consent Date

APPENDIX C: PRIVATE PROVIDER INTERVIEW

IMMUNIZE KANSAS KIDS
PRIVATE PROVIDER INTERVIEW

1. What are some of the clinical focus areas that are most important for your clinic? Can you describe for me how providing immunization services compares to these clinical areas?

2. Tell me what you think about the delivery and timing of immunization services in Kansas?

   a. What are some positive aspects?
   b. What are some negative aspects?

3. How would you describe the process and methods that Kansas uses to ensure that all children are immunized on time?

4. Why do you think that Kansas chose these processes and methods for delivering immunizations to children?

5. Please describe the appropriateness or effectiveness of these methods.

6. What are some alternatives for delivery of immunization services that would work for Kansas?

   a. Are some alternatives better than others?
   b. Why or why not?

7. How would these alternatives affect your clinic's practice related to delivery of immunization services?

   a. Which of these would be positive effects? Why?
   b. Which would be barriers to delivery of immunization services by your clinic? Why?

8. What influenced your clinic's decision to (provide, not provide) immunization services to your patients?

   a. Which of the factors that you just mentioned do you consider the most important to your decision? Why?
   b. Which is the least important? Why?

   [If VFC emerges as an important factor, probe for whether it is a determining factor for offering immunization services to indigent children.]

9. Do you know about the Vaccines for Children (VCF) program?

    a. If yes, are you enrolled?
    b. [If no, provide a description of VCF and then ask:] Does the availability of this program have the potential to influence your immunization practices?

        i. If yes, why?
        ii. If no, why not?

10. Are your patients satisfied with your choice of immunization practice? How do you know?

11. Why do you think that other Kansas clinics have different immunization practices (i.e., either do or do not provide immunization services) from your clinic's practices? [The phrasing of this question will depend on the answer to Q8.]

12. How would you describe the interaction between private providers in your area and your local health department to assure that children receive their shots on time?

13. How would you describe the interaction between your clinic and your local health department to assure that children receive their shots on time?

14. What would you prefer to see happen at the state level to address current concerns with respect to numbers of children immunized on schedule?

15. What are some things that might/could happen at the state level that would influence your practice related to immunization services?

16. Would this be better or worse for your clinic? How?

17. How do you think a state mandated change for immunization practice, e.g., mandated immunization registry reporting or requiring insurance coverage for all immunizations, would affect your patients? Why do you believe this?

APPENDIX D: LOCAL HEALTH DEPARTMENT INTERVIEW

IMMUNIZE KANSAS KIDS
LOCAL HEALTH DEPARTMENT INTERVIEW

1. How important do you believe that providing immunization services is relative to other public health activities?

2. Tell me what you think about the delivery and timing of immunization services in Kansas?

    a. What are some positive aspects?
    b. What are some negative aspects?

3. How would you describe the process and methods used in Kansas to ensure that all children are immunized on time?

4. Why do you think that these processes and methods for delivering immunizations to children are used in Kansas?

5. Please describe the appropriateness or effectiveness of these methods.

6. What are some alternatives for delivery of immunization services that would work for Kansas?

    a. Are some alternatives better than others?
    b. Why or why not?

7. How would these alternatives affect your health department's practice related to delivery of immunization services?

    a. Which of these would be positive effects? Why?
    b. Which would be barriers to delivery of immunization services by your health department? Why?

8. Why do you think that private providers in Kansas have different immunization practices? (Some of them provide immunization services to their clients, while others do not.)

9. How would you describe the respective roles of local health departments throughout the state and private providers in assuring that children receive their shots on time?

10. How would you describe the interaction between <u>your</u> local health department and the private providers in your area to assure that children receive their shots on time?

11. Do you think that your clients are satisfied with how their children receive immunizations? [For this question focus on system issues, i.e., are parents satisfied with the immunization delivery system in the state?]

12. Do you think that your clients are satisfied with how immunizations are delivered in your health department? How do you know?

13. What would you prefer to see happen at the state level to address current concerns with respect to numbers of children immunized on schedule?

14. What are some things that might/could happen at the state level that would influence the way you deliver immunization services? Would this be better or worse for your health department? How?

15. How do you think a state-mandated change for immunization practice, e.g., mandated immunization registry reporting or requiring insurance coverage for all immunizations, would affect your clients and your local health department?

APPENDIX E: PARENT INTERVIEW

IMMUNIZE KANSAS KIDS
PARENT INTERVIEW

1. The information letter we sent to you about our project suggested that you have a copy of [CHILD'S NAME] immunization or shot records with you to help with this interview. Were you able to locate these records? If yes, go to Q2. If not, go to Q18.

2. Please indicate the date and age of your child when the following shots were given to your child?

   a. Hepatitis B: #1, #2, #3
   b. DPT: #1, #2, #3, #4
   c. Hib: #1, #2, #3, #4
   d. Polio: #1, #2, #3
   e. MMR: #1, #2
   f. Varicella

   [PROMPT: Use Excel logarithm for establishing when these immunizations should have been given for this child.]

If immunizations are complete and up to date go to Q3. If some immunizations are not complete go to Q20.

3. How did you know when to bring your child for his/her shots?

4. Were all of your child's shots received at the same doctor's office or clinic?

   a. If yes, what was the name of the doctor's office or clinic?
   b. If not, why not?
   c. How many different doctor's offices or clinics did you take your child to for shots?
   d. Can you tell me the names of all or some of those doctor's offices or clinics?

5. What did you like best/least about the way your doctor(s) delivered the shots to your family?

   [Prompts: costs, location, done in conjunction with a visit for something else]

6. Did you have any problems with getting your child's shots on time or with following your doctor/nurse's recommendations for scheduling your child's shots? If yes, what were these?

7. Is/Was there anything that could assist/have assisted you with completing the shot schedule for your child on time?

8. What was the easiest part about getting your child immunized?

9. What was the hardest part of getting your child immunized?

10. Some parents [SAY "as you have experienced with your family" IF INDICATED BY ANSWER TO Q6] have difficulty following the shot schedule. Can you think of reasons [OPTIONAL: that might be different or in addition to what you experienced] for why this might be?

11. Tell me what you think about the recommended shot schedule for children.

    [PROMPT: Have immunization schedule accessible for reference.]

12. How do you know when it is time for your child to receive another shot?

13. How do you keep track of the shots that your child has received?

14. What could doctors do to help parents follow the recommended shot schedule?

15. What could local health departments do to help parents follow the recommended shot schedule?

16. What could the Kansas state health department do to help parents follow the recommended shot schedule?

17. Is there anything that you think needs to be changed about the way children get their shots?

END OF INTERVIEW.

18. What prevented you from having your child's shot records available today?

19. To the best of your ability to recall, please tell me when and at what age your child received the following shots:

    a. Hepatitis B: #1, #2, #3
    b. DPT: #1, #2, #3, #4
    c. Hib: #1, #2, #3, #4
    d. Polio: #1, #2, #3
    e. MMR: #1, #2
    f. Varicella

    [PROMPT: Use Excel logarithm for establishing when these immunizations should have been given for this child.]

If immunizations are complete and up-to-date go to Q3. If some immunizations are not complete go to Q20.

20. Can you tell me about what you have dealt with in trying to keep [CHILD'S NAME]'s shots complete or up-to-date? [Probe for specific problems in non-judgmental language.]

GO TO QUESTION 3.