

## FAMILY EXPERIENCES WITH COORDINATION OF CARE SURVEY TELEPHONE INTERVIEW VERSION

LABEL	VALUE	TEXT	INSTRUCTIONS
1.		Your child's main provider is the doctor, physician assistant, nurse or other health care provider who knows the most about your child's health, and who is in charge of your child's care overall.	
1A.	OPEN TEXT (100 CHARACTERS)	What is the name of your child's main provider?	
1B.	EMPTY	The questions in this survey will refer to [FILL 1A.] as "your child's main provider." Please think of that person as you answer the questions.	
2-INTRO	EMPTY	This first set of questions is about the people who help you manage care, treatment and services for your child.	
2.	0=NO (GO TO 17-INTRO) 1=YES (GO TO 3A)  8 = DON'T KNOW (GO TO 3A) 9 = REFUSED (GO TO 3A)	In the last 12 months, did your child visit more than one doctor's office or use more than one kind of health care service, such as physical or speech therapy, or community service, such as home health care or transportation services?  IF NEEDED: Other examples of community services are early intervention programs, respite care, and parent or caregiver support services.	
3A.	0=NO (GO TO 3B) 1=YES (GO TO 4)  8 = DON'T KNOW (GO TO 3B) 9 = REFUSED (GO TO 3B)	Did anyone in the main provider's office help you to manage your child's care or treatment from different doctors or care providers?	

LABEL	VALUE	TEXT	INSTRUCTIONS
3B.	0=NO (GO to #17 Intro) 1=YES (GO TO 3C)  8 = DON'T KNOW (GO TO 17 INTRO) 9 = REFUSED (GO TO 17 INTRO)	Did anyone <u>outside</u> of [1A]'s office help you to manage your child's care or treatment from different doctors or care providers?	
3C.	<ol style="list-style-type: none"> <li>1. Another provider from a different office/clinic</li> <li>2. A care coordinator who isn't part of [FILL 1A's] office staff</li> <li>3. A social worker who isn't part of [1A's] office staff</li> <li>4. A care or case manager who isn't part of [1A's] office staff</li> <li>5. Someone else who isn't part of [1A's] office staff</li> </ol>	Who was it that helped you? If more than one person helped you, we want to know the person who helped you most often in the last 12 months.	ALL GO TO 5A
4.	<ol style="list-style-type: none"> <li>1. Your child's main provider</li> <li>2. Another doctor or nurse in the main provider's office</li> <li>3. A clerk or receptionist in the main provider's office</li> <li>4. A care coordinator in the main provider's office</li> <li>5. A social worker in the main provider's office</li> <li>6. A care manager or case manager in the main provider's office</li> <li>7. Someone else in the main provider's office</li> </ol> 8 = DON'T KNOW 9 = REFUSED	Who in the main provider's office helped you? If more than one person helped you, we want to know the person who helped you most often in the last 12 months.	
5a.	1 = Yes, definitely 2 = Yes, somewhat 3 = No  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the person who helped you with managing your child's care know the important information about your child's health and care needs? Would you say:	

LABEL	VALUE	TEXT	INSTRUCTIONS
5b.	1 = Yes, definitely 2 = Yes, somewhat 3 = No  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the person who helped you with managing your child's care seem informed and up-to-date about the care your child got from other providers? Would you say:	
5c.	1 = Yes, definitely 2 = Yes, somewhat 3 = No  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the person who helped you with managing your child's care support your decisions about what is best for your child's health and treatment?	
5d	1 = Yes, definitely 2 = Yes, somewhat 3 = No 4 = N/A, my child hasn't needed to have visits with other providers during the last 12 months  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the person who helped you with managing your child's care help you to get appointments to visit other providers?	
5e	1 = Yes, definitely 2 = Yes, somewhat 3 = No 4 = N/A, my child hasn't needed special medical equipment during the last 12 months  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the person who helped you with managing your child's care help you to get special medical equipment your child needed like a special bed, wheelchair, or feeding tube supplies?	
6.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did you know how to contact the person who helped you with managing your child's care when you needed help or had a question?	
7.	0=NO (GO TO 11.) 1=YES  8 = DON'T KNOW 9 = REFUSED	In the last 3 months, did this person contact you without you getting in touch with them first?	

LABEL	VALUE	TEXT	INSTRUCTIONS
8.	CHOOSE ALL 1. During a visit to the main provider's office 2. By telephone 3. By email 4. By mail 5. Some other way 8 = DON'T KNOW 9 = REFUSED	How did he or she contact you? Please tell me all the ways you were contacted. Was it:	
9.	1. Never 2. Sometimes 3. Usually 4. Always  8= DON'T KNOW 9 = REFUSED	<u>In the last 3 months</u> , when the person who helped you with managing your child's care contacted you, how often did he or she ask if you had any concerns about your child's health or treatment?	
10.	1. Never 2. Sometimes 3. Usually 4. Always  8= DON'T KNOW 9 = REFUSED	<u>In the last 3 months</u> , when the person who helped you with managing your child's care contacted you, how often did he or she ask if your child's health had changed in any way?	
11.	1. Never 2. Sometimes 3. Usually 4. Always  8= DON'T KNOW 9 = REFUSED	Overall, how often did you get the help you needed to manage your child's care or treatment from different doctors or care providers <u>in the last 12 months</u> ?	
12.	1. Very satisfied 2. Somewhat satisfied 3. Somewhat dissatisfied 4. Very dissatisfied	Overall, how satisfied or dissatisfied were you with the help you received in managing your child's care or treatment <u>in the last 12 months</u> ?	
13-INTRO		The next few questions ask about your experiences with getting care for your child from specialists.	

LABEL	VALUE	TEXT	INSTRUCTIONS
13.	0=NO (GO TO 15-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	Specialists are doctors like surgeons, heart doctors, allergy doctors, mental health doctors, and other doctors who specialize in one area of health care. During the <u>last 12 months</u> , did the main provider tell you that your child needed to see a specialist?	
14.	1. Never 2. Sometimes 3. Usually 4. Always  8= DON'T KNOW 9 = REFUSED	Did the person who helped you with managing your child's care contact you to make sure your child got an appointment to see a specialist?	
15-INTRO		The next few questions ask about your experiences with getting <u>community services</u> for you or your child.	
15.	0=NO (GO TO 17-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	Community services are services to help maintain your and your child's health and well-being, which may or may not be ordered by one of your child's doctors. This can include things like home health care, early intervention programs, respite care, help with transportation, and parent or caregiver support services. In the <u>last 12 months</u> , did you or your child need or use community services?	
16.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the person who helped you with managing your child's care help you to get the community services you or your child needed?	

LABEL	VALUE	TEXT	INSTRUCTIONS
17-Intro		The next set of questions asks about different ways in which you might get information about the care your child is receiving. We are interested in summaries you might have received after visiting the main provider's office or after your child was in the hospital.	
17.	0=NO (GO TO 21) 1=YES  8 = DON'T KNOW 9 = REFUSED	A <u>written visit summary</u> sums up what happened during your child's visit to a health care provider. A written visit summary can be available on paper, on a web site, through an app, or sent by email. In the last 12 months, did anyone at the main provider's office give you a written visit summary after your child's visits?	
18a.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	How often did the written visit summaries you got from the main provider's office include a list of your child's health problems at the time of the visit?	
18b.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	How often did the written visit summaries you got from the main provider's office include an up-to-date list of all the prescription medicines your child is taking?	
18c.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	How often did the written visit summaries you got from the main provider's office include an up-to-date list of all the over the counter medicines your child is taking?	
18d.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	How often did the written visit summaries you got from the main provider's office include a list of your child's allergies?	

LABEL	VALUE	TEXT	INSTRUCTIONS
18e.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	How often did the written visit summaries you got from the main provider's office include the names of all the specialist doctors who help care for your child?	
18f.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	How often did the written visit summaries you got from the main provider's office include the plan for follow-up care for your child after the visit?	
18g.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	How often did the written visit summaries you got from the main provider's office include what to do if your child had a problem after the visit?	
19.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, how often was the written visit summary you got from the main provider's office easy to understand?	
20.	1. Never 2. Sometimes 3. Always  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, how often was the written visit summary you got from the main provider's office useful to you and your family?	
21.	0=NO (GO TO 26-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	Has your child had an overnight hospital stay in the last 12 months?	

LABEL	VALUE	TEXT	INSTRUCTIONS
22.	0=NO (GO TO 25) 1=YES  8 = DON'T KNOW 9 = REFUSED	A written hospital stay summary sums up all that happened during your child's hospital stay. A written hospital stay summary can be available on paper, on a web site, through an app, or sent by email.  <u>The last time your child was in the hospital</u> , did your child's doctor, nurse, or other hospital staff give you a written hospital stay summary on the day your child left the hospital?	
23a.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the written hospital stay summary you got include a list of the health problems your child had when he or she left the hospital?	
23b.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the written hospital stay summary you got include a list of all the prescription medicines your child was taking when he or she left the hospital?	
23c.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the written hospital stay summary you got include a list of all the over the counter medicines your child was taking when he or she left the hospital?	
23d.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the written hospital stay summary you got include a list of your child's allergies?	
23e.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the written hospital stay summary you got include the names of all the specialist doctors who helped care for your child during the hospital stay?	



LABEL	VALUE	TEXT	INSTRUCTIONS
23f.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the written hospital stay summary you got include what the planned follow-up care was for your child after the hospital stay?	
23g.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Did the written hospital stay summary you got include who to call if your child had problems after the hospital stay?	
24.	1. Yes, definitely 2. Yes, somewhat 3. No 8 = DON'T KNOW 9 = REFUSED	Was the information in the written hospital stay summary you got easy to understand?	
25.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Hospital rounds are the daily visits the health care team makes to patients in the hospital to check up on how they are doing and how well the treatment is working, and what the plan for the day will be. Nurses, doctors, medical students and other health care providers may join hospital rounds to discuss the plan for the day for every patient. <u>The last time your child was in the hospital</u> , did any of your child's doctors or nurses invite you to take part in hospital rounds?	
26-Intro		In addition to information you may get after a visit or a hospital stay, some providers make information available through a web site or an app. We are interested in your experiences with this way of getting information about your child's health and health care.	

LABEL	VALUE	TEXT	INSTRUCTIONS
26.	0=No (GO TO 29-INTRO) 1=Yes 2= Or are you not sure if the main provider's office has a web site or app? (GO TO 29-INTRO)  9 = REFUSED  <i>Yes</i> <i>No → If No, go to #29-Intro</i> <i>Or are you not sure if the main provider's office has a web site or app? → If not sure, go to #29-Intro</i>	In the last 12 months, did the main provider's office have a web site or app you could use between visits to look up information about your child's visits and health care? Would you say:	
27.	0=No 1=Yes 2=Or your child did not get any shots or immunizations in the last 12 months? 8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the main provider's web site or app have a list of the <u>shots or immunizations</u> your child has received? Would you say:	
28.	0=No 1=Yes 2=Or your child did not take any medications in the last 12 months? 8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the main provider's web site or app have a list of your child's <u>medications</u> ? Would you say:	

LABEL	VALUE	TEXT	INSTRUCTIONS
29-Intro		The next set of questions asks about three different types of written care plans the main provider may have created for your child: shared care plans, emergency care plans, and transition care plans. We are interested in your experiences, if any, with these different types of plans.	
29.	0=NO (GO TO 32-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	A shared care plan is a written document that contains information about your child's active health problems, medicines he or she is taking, special considerations that all people caring for your child should know, goals for your child's health, growth and development, and steps to take to reach those goals.  Has the main provider created a <u>shared care plan</u> for your child?	
30.	0=NO (GO TO 32-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	Do you have a copy of your child's shared care plan?	
31.	0= No 1= Yes 2= Or are there no goals written in your child's shared care plan?  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, has the main provider or anyone from the main provider's office talked with you about the progress your child was making toward the goals written in his or her shared care plan? Would you say:	

LABEL	VALUE	TEXT	INSTRUCTIONS
32-Intro		<p>An emergency care plan is a written document that contains important information about your child's health, treatment and medications. It also includes special considerations that all people caring for your child should know, for example, how your child lets you know he or she is in pain, or how to communicate with your child if he or she can't hear or speak. Families often bring the emergency care plan when they take a child to an emergency room or urgent care clinic.</p>	
32.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Has the main provider created an emergency care plan for your child?	
33-INTRO		If your child is at least 15 years old, we are interested in your experiences with making plans for your child's care when he or she becomes an adult. This is sometimes called a transition plan.	
33.	0=NO (GO TO 35-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	Is your child age 15 or older?	
34.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	Has the main provider created a written transition plan that summarizes how your child's care will change and how it will stay the same when he or she becomes an adult?	
35-Intro		The next set of questions asks about your child's experiences in school.	

LABEL	VALUE	TEXT	INSTRUCTIONS
35.	0=NO (GO TO 38-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did your child attend school?	
36.	0=NO (GO TO 38-INTRO) 1=YES  8 = DON'T KNOW 9 = REFUSED	Because of his or her health condition does your child have any difficulty learning, understanding, or paying attention in class?	
37.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did anyone from the main provider's office contact staff at your child's school to make sure they understood how your child's health condition affected his or her ability to learn, understand or pay attention in class?	
38-Intro		This last set of questions is about you and your child. This information will help us to describe the parents and children who take part in this survey.	
38.	1. Very well 2. Well 3. Not well 4. Not at all well	How well do you speak English?	
39.	0=NO (GO TO 46) 1=YES  8 = DON'T KNOW 9 = REFUSED	Do you speak a language other than English at home?	
40.	1. SPANISH 2. SOME OTHER LANGUAGE  8 = DON'T KNOW 9 = REFUSED	What is the language you speak at home?	
41.	1. ENGLISH (GO TO #46) 2. ANOTHER LANGUAGE 8 = DON'T KNOW 9 = REFUSED	Do you prefer to talk with your child's doctors and care providers in English or in another language?	

LABEL	VALUE	TEXT	INSTRUCTIONS
42.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did the main provider speak to you in the language you prefer?	
43.	0=NO 1=YES  8 = DON'T KNOW 9 = REFUSED	In the last 12 months, did anyone in the main provider's office speak to you in the language you prefer?	
44.	1. No visits (GO TO #46) 2. Some visits 3. Most visits 4. All visits 8 = DON'T KNOW 9 = REFUSED	A medical interpreter is a professional who helps you talk with doctors and other providers who do not speak your language. The interpreter can do this over the phone or in-person. In the last 12 months, how often did you need an interpreter during a visit to the main provider?	
45.	1. Never 2. Sometimes 3. Usually 4. Always 8 = DON'T KNOW 9 = REFUSED	When you needed a professional interpreter during a visit to the main provider, how often was an interpreter available?	
46.	1. YES, HISPANIC OR LATINO 2. NO, NOT HISPANIC OR LATINO 8 = DON'T KNOW 9 = REFUSED	Is <u>this child</u> of Hispanic or Latino origin or descent?	
47.	1. White 2. Black or African American 3. Asian 4. Native Hawaiian or Other Pacific Islander 5. American Indian or Alaska Native 6. Other 8 = DON'T KNOW 9 = REFUSED	What is <u>this child's</u> race? Please choose one or more from this list:	

LABEL	VALUE	TEXT	INSTRUCTIONS
48.	18 TO 24 25 TO 34 35 TO 44 45 TO 54 55 TO 64 65 TO 74 75 OR OLDER 8 = DON'T KNOW 9 = REFUSED	What is <u>your</u> age?	
49.	1. MALE 2. FEMALE 8 = DON'T KNOW 9 = REFUSED	I'm required to ask, are <u>you</u> male or female?	
50.	1. YES, HISPANIC OR LATINO 2. NO, NOT HISPANIC OR LATINO 8 = DON'T KNOW 9 = REFUSED	Are <u>you</u> of Hispanic or Latino origin or descent?	
51.	1. White 2. Black or African American 3. Asian 4. Native Hawaiian or Other Pacific Islander 5. American Indian or Alaska Native 6. Other 8 = DON'T KNOW 9 = REFUSED	What is <u>your</u> race? Please choose one or more from this list.	
52.	1. 8th grade or less 2. Some high school, but did not graduate 3. High school graduate or GED 4. Some college or 2-year degree 5. 4-year college graduate 6. More than 4-year college degree 8 = DON'T KNOW 9 = REFUSED	What is the highest grade or level of school that <u>you</u> have completed?	
THANKS	EMPTY	That's the end of the survey. Thank you very much for participating. Do you have any questions for me before we end the call?	