

YOUR EXPERIENCES WITH YOUR CHILD'S HEALTH CARE



*Answer the questions in this survey for the child
named in the letter that came with this survey.*

Survey Instructions

Answer each question by marking the box to the left of your answer.

You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

- Yes → **If Yes, go to #1 on page 1**
- No

Your Child's Main Provider

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. What is the name of your child's main provider:

The questions in this survey will refer to this provider as "the main provider." Please think of that person as you answer the questions.

Getting Help to Manage Your Child's Care

These first questions are about the people in the main provider's office who may help you manage care, treatment and services for your child.

2. 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?

- Yes
- No → **If No, go to #17**

3a. Did anyone in the main provider's office help you to manage your child's care or treatment from different doctors or care providers?

- Yes → **If Yes, go to #4**
- No

3b. Did anyone outside the main provider's office help you to manage your child's care or treatment from different doctors or care providers?

- Yes
- No → **If No, go to #17**

3c. 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.

- Another provider from a different office/clinic
- A care coordinator who isn't a part of the main provider's office staff
- A social worker who isn't a part of the main provider's staff
- A care or case manager who isn't a part of the main provider's office staff
- Someone else who isn't a part of the main provider's office

4. Who in the main provider's office helped you? If more than one person helped you, mark the person who helped you most often in the last 12 months.

- Your child's main provider
- Another doctor or nurse in the main provider's office
- A clerk or receptionist in the main provider's office
- A care coordinator in the main provider's office
- A social worker in the main provider's office
- A care manager or case manager in the main provider's office
- Someone else in the main provider's office

5. In the last 12 months, did the person who helped you with managing your child's care...

	<u>Yes</u> <u>Definitely</u>	<u>Yes</u> <u>Somewhat</u>	<u>No</u>
a) Know the important information about your child's health and care needs?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Seem informed and up-to-date about the care your child got from other providers?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Support your decisions about what is best for your child's health and treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Help you to get appointments to visit other providers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Not applicable, my child didn't need to see any other providers

e) Help you to get special medical equipment your child needed like a special bed, wheelchair, or feeding tube supplies?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Not applicable, my child didn't need any special medical equipment

6. 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?

- Yes
- No

7. **In the last 3 months**, did this person contact you without you getting in touch with them first?

- Yes
- No → **If No, go to #11**

8. How did he or she contact you? Please mark one or more.

- During a visit to the main provider's office
- By telephone
- By email
- By mail
- Some other way

9. **In the last 3 months**, 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?

- Never
- Sometimes
- Usually
- Always

10. **In the last 3 months**, 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**?

- Never
- Sometimes
- Usually
- Always

CC SERVICE OUTCOMES

11. Overall, how often did you get the help you needed to manage your child's care or treatment from different doctors or care providers **in the last 12 months**?

- Never
- Sometimes
- Usually
- Always

12. Overall, how satisfied or dissatisfied were you with help you received in managing your child's care or treatment **in the last 12 months**?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied

Your Child's Care from Specialists

The next few questions ask about your experiences with getting care for your child from specialists.

13. 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 **last 12 months**, did the main provider tell you that your child needed to see a specialist?

- Yes
- No → **If No, go to #15**

14. 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?

- Yes
- No
- I did not get help managing my child's care

Getting Community Services for You and Your Child

The next few questions ask about your experiences with getting **community services** for you or your child.

15. 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 **last 12 months**, did you or your child need or use community services?

- Yes
- No → **If No, go to #17**

16. Did the person who helped you with managing your child's care help you to get the community services you or your child needed?

- Yes
- No

Getting Summaries of Your Child's Visits or Hospital Stays

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. A **written visit summary** 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?

- Yes
- No → **If No, go to #21**

18. How often did the written visit summaries you got from the main provider's office include...

	<u>Never</u>	<u>Sometimes</u>	<u>Always</u>
a) A list of your child's health problems at the time of the visit?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) An up-to-date list of all the prescription medicines your child is taking?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) An up-to-date list of all the over the counter medicines your child is taking?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) A list of your child's allergies?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) The names of all the specialist doctors who help care for your child?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) The plan for follow-up care for your child after the visit?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) What to do if your child had a problem after the visit?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. In the last 12 months, how often was the written visit summary you got from the main provider's office easy to understand?

- Never
- Sometimes
- Always

20. 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?

- Never
- Sometimes
- Always

21. Has your child had an overnight hospital stay in the last 12 months?

- Yes
- No → **If No, go to #26**

22. 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.

The last time your child was in the hospital, 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?

- Yes
- No → **If No, go to #25**

23. Did the written hospital stay summary you got include...

	<u>Yes</u>	<u>No</u>
a) A list of the health problems your child had when he or she left the hospital?	<input type="checkbox"/>	<input type="checkbox"/>
b) A list of all the prescription medicines your child was taking when he or she left the hospital?.....	<input type="checkbox"/>	<input type="checkbox"/>
c) A list of all the over the counter medicines your child was taking when he or she left the hospital?.....	<input type="checkbox"/>	<input type="checkbox"/>
d) A list of your child's allergies?	<input type="checkbox"/>	<input type="checkbox"/>
e) The names of all the specialist doctors who helped care for your child during the hospital stay?.....	<input type="checkbox"/>	<input type="checkbox"/>
f) What the planned follow-up care was for your child after the hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>
g) Who to call if your child had problems after the hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>

24. Was the information in the written hospital stay summary you received easy to understand?

- Yes, definitely
- Yes, somewhat
- No

25. 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. **The last time your child was in the hospital**, did any of your child's doctors or nurses invite you to take part in hospital rounds?

- Yes
- No

Getting Information about Your Child's Health and Health Care In Between Visits

In addition to information you may have received 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.

26. 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?

- Yes
- No → **If No, go to #29**
- I don't know if my child's main provider's office has a web site or app → **If Don't know, go to #29**

27. In the last 12 months, did the main provider's web site or app have a list of the **shots or immunizations** your child has received?

- Yes
- No
- My child has not received any shots or immunizations in the last 12 months
- I don't know if the web site or app for my child's main provider's office has a list of my child's shots or immunizations

28. In the last 12 months, did the main provider's web site or app have a list of your child's **medications**?

- Yes
- No
- My child has not taken any medications in the last 12 months
- I don't know if the web site or app for my child's main provider's office has a list of my child's medications

Your Child's Care Plans

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. 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 **shared care plan** for your child?

- Yes
- No → **If No, go to #32**

30. Do you have a copy of your child's shared care plan?

- Yes
- No → **If No, go to #32**

31. 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?

- Yes
- No
- My child's shared care plan does not have written goals

32. 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.

Has the main provider created an emergency care plan for your child?

- Yes
- No

33. 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.

Is your child age 15 or older?

- Yes
- No → **If No, go to #35**

34. 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?

- Yes
- No
- I don't know

Your Child's Experiences in School

The next set of questions asks about your child's experiences in school.

35. In the last 12 months, did your child attend school?

- Yes
- No → **If No, go to #38**

36. Because of his or her health condition does your child have any difficulty learning, understanding, or paying attention in class?

Yes

No → **If No, go to #38**

37. 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?

Yes

No

I don't know

About You and Your Child

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. How well do you speak English?

- Very well
- Well
- Not well
- Not at all well

39. Do you speak a language other than English at home?

- Yes
- No → **If No, go to #46**

40. What is the language you speak at home?

- Spanish
- Some other language



Please print other language: _____

41. Do you prefer to talk with your child's doctors and care providers in English or in another language?

- English → **If English, go to #46**
- Another language

42. In the last 12 months, did the main provider speak to you in the language you prefer?

- Yes
- No

43. In the last 12 months, did anyone in the main provider's office speak to you in the language you prefer?

- Yes
- No

44. 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 this last 12 months, how often did you need an interpreter during a visit to the main provider?

- No visits → **If No visits, go to #46**
- Some visits
- Most visits
- All visits

45. When you needed a professional interpreter during a visit to the main provider, how often was an interpreter available?

- Never
- Sometimes
- Usually
- Always

46. Is **this child** of Hispanic or Latino origin or descent?

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

47. What is **this child's** race? Mark one or more.

- White
- Black or African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian or Alaska Native
- Other

48. What is **your** age?

- Under 18
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or older

49. Are **you** male or female?

- Male
- Female

50. Are **you** of Hispanic or Latino origin or descent?

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

51. What is **your** race? Mark one or more.

- White
- Black or African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian or Alaska Native
- Other

52. What is the highest grade or level of school that you have completed?

- 8th grade or less
- Some high school, but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree

Thank you for completing this survey!