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 #13**

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 #13**

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…

Yes Yes

Definitely Somewhat No

a) Know the important information about your

child’s health and care needs? ☐ ☐ ☐

b) Seem informed and up-to-date about the care your

child got from other providers? ☐ ☐ ☐

c) Support your decisions about what is best for your

child’s health and treatment? ☐ ☐ ☐

d) Help you to get appointments to visit

other providers? ☐ ☐ ☐

☐ 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? ☐ ☐ ☐

☐ Not applicable, my child didn’t need any special medical equipment

6. **In the last 3 months**, did the person who helped you with managing your child’s care contact you without you getting in touch with them first?

* Yes
* No 🡪 **If No, go to #9**

7. **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

8. **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

**Your Child’s Care from Specialists**

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

9. 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 #11**

10. 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.

11. Community services are services to help maintainyour 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 homehealth 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 #13**

12. 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.

13. 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 #15**

14. How often did the written visit summaries you got from the main provider’s office include…

Never Sometimes Always

a) A list of your child’s health problems at the

time of the visit? ☐ ☐ ☐

b) An up-to-date list of all the prescription

medicines your child is taking? ☐ ☐ ☐

c) An up-to-date list of all the over the counter

medicines your child is taking? ☐ ☐ ☐

d) A list of your child’s allergies?.............................. ☐ ☐ ☐

e) The names of all the specialist doctors

who help care for your child? ☐ ☐ ☐

f) The plan for follow-up care for your child

after the visit? ☐ ☐ ☐

g) What to do if your child had a problem

after the visit? ☐ ☐ ☐

**Your Child’s Care Plans**

The next set of questions asks about a type of written care plan the main provider may have created for your child called a shared care plan. We are interested in your experiences, if any, with this type of plan.

15. 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

**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.

16. How well do you speak English?

* + Very well
  + Well
  + Not well
  + Not at all well

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

* + Yes
  + No 🡪 **If No, go to #22**

18. What is the language you speak at home?

* + Spanish
  + Some other language



*Please print other language:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_*

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

* English 🡪 **If English, go to #22**
* Another language

20. 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 #22**
* Some visits
* Most visits
* All visits

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

* Never
* Sometimes
* Usually
* Always

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

* Yes, Hispanic or Latino
* No, not Hispanic or Latino

23**.** 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

24.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

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

* Male
* Female

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

* Yes, Hispanic or Latino
* No, not Hispanic or Latino

27**.** 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

28**.** 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!**