

## Survey of Parents of Adolescents with Congenital Heart Defects

Thank you for taking the time to complete this short survey. We are hoping to learn more about the experiences of parents arranging specialty medical care for their children with congenital heart defects. The information you provide here will help us identify barriers to accessing care as well as those things that help you get care. Your participation is completely voluntary and your responses will be secured. We appreciate the opportunity to learn from your experiences.

Please answer all questions about your child with a congenital heart defect or heart problem at birth.

### Recent Healthcare Experiences:

In this section, we will ask you about recent healthcare use and experiences for your child with a congenital heart defect.

**Please circle the letter corresponding to your response for each question.**

1. When was your child last seen by **any** healthcare provider?
  - a) Within the past 6 months
  - b) Greater than 6 months, but less than 1 year ago
  - c) Greater than 1 year, but less than 2 years ago
  - d) Greater than 2 years, but less than 3 years ago
  - e) It has been greater than 3 years
  
2. When was your child last seen by a pediatric cardiologist (heart doctor who sees children)?
  - a) Within the past 6 months
  - b) Greater than 6 months, but less than 1 year ago
  - c) Greater than 1 year, but less than 2 years ago
  - d) Greater than 2 years, but less than 3 years ago
  - e) It has been greater than 3 years
  - f) My child has never been seen by a pediatric cardiologist → Skip to question 4
  
3. At what location did your child last see a pediatric cardiologist (heart doctor who sees children)?
  - a) Medical center or hospital office
  - b) Private office
  - c) Don't know
  
4. Have you had, tried to have, or wanted to have any interaction with the healthcare system for your child with a congenital heart defect (any doctor, provider, service, appointment scheduling, filling prescription refills, etc.) in the past three months?

- a) Yes → Continue to the next question  
 b) No → Skip to question 6 (the Pediatric Cardiac Quality of Life Inventory)

5. Problems getting health care for my child

Parents often face barriers when trying to get health care for their children. We are interested in the kinds of things that interfere with getting health care for your child(ren) with CHD. Please rate how much of a problem each of the following is for you.

**Please answer each question by completely shading the circle so that it looks like this:** ●

	Never	Almost Never	Sometimes	Often	Almost Always
In the last 3 months, how often did the health care system work well for your child?	(0)	(1)	(2)	(3)	(4)

How often were each of the following barriers a problem in the past 3 months when trying to get health care for your child with CHD:

<b>Problems with:</b>	Never	Almost Never	Sometimes	Often	Almost Always
Getting to the doctor's office	(0)	(1)	(2)	(3)	(4)
Getting hold of the doctor's office or clinic by phone	(0)	(1)	(2)	(3)	(4)
Having to wait too many days for an appointment	(0)	(1)	(2)	(3)	(4)
Getting care after hours or on the weekends	(0)	(1)	(2)	(3)	(4)
Having to take care of household responsibilities	(0)	(1)	(2)	(3)	(4)
Having to take time off work	(0)	(1)	(2)	(3)	(4)
Having to wait too long in the waiting room	(0)	(1)	(2)	(3)	(4)
Knowing how to make the health care system work for you	(0)	(1)	(2)	(3)	(4)
Meeting the needs of other family members	(0)	(1)	(2)	(3)	(4)
The cost of health care	(0)	(1)	(2)	(3)	(4)
Doctors or nurses not fluent in your language	(0)	(1)	(2)	(3)	(4)
Doctors or nurses who speak in a way that is too technical or medical	(0)	(1)	(2)	(3)	(4)
Getting referrals to specialists	(0)	(1)	(2)	(3)	(4)
Understanding doctor's orders	(0)	(1)	(2)	(3)	(4)
Having enough information about how the health care system works	(0)	(1)	(2)	(3)	(4)
Needing to be more 'savvy' or knowledgeable about getting health care	(0)	(1)	(2)	(3)	(4)

Getting enough help with paperwork or forms	(0)	(1)	(2)	(3)	(4)
Offices and staff that are not child-friendly	(0)	(1)	(2)	(3)	(4)
<b>Problems with:</b>	Never	Almost Never	Sometimes	Often	Almost Always
Mistakes made by doctors or nurses	(0)	(1)	(2)	(3)	(4)
Worrying that doctors and nurses will not do what is right for your child	(0)	(1)	(2)	(3)	(4)
Doctors treating the symptom without finding out the cause of the illness	(0)	(1)	(2)	(3)	(4)
Getting a thorough examination	(0)	(1)	(2)	(3)	(4)
Lack of communication between my child's <u>doctor</u> and <u>others</u> in the health care system	(0)	(1)	(2)	(3)	(4)
Lack of communication between different <u>parts of the health care system</u>	(0)	(1)	(2)	(3)	(4)
Feeling like <u>doctors</u> are trying to give as little service as possible	(0)	(1)	(2)	(3)	(4)
Feeling like the <u>health care system</u> is trying to give as little service as possible	(0)	(1)	(2)	(3)	(4)
Impatient doctors	(0)	(1)	(2)	(3)	(4)
Intimidating doctors	(0)	(1)	(2)	(3)	(4)
Rude office staff	(0)	(1)	(2)	(3)	(4)
Uncaring office staff	(0)	(1)	(2)	(3)	(4)
Getting the doctor to listen to you	(0)	(1)	(2)	(3)	(4)
Getting your questions answered	(0)	(1)	(2)	(3)	(4)
Not knowing what to expect from one visit to the next	(0)	(1)	(2)	(3)	(4)
Being judged on your appearance, your ancestry, or your accent	(0)	(1)	(2)	(3)	(4)
Doctors rushing you and your child through the visit	(0)	(1)	(2)	(3)	(4)
Disagreeing with the doctor's orders	(0)	(1)	(2)	(3)	(4)
Doctors not believing in home or traditional remedies	(0)	(1)	(2)	(3)	(4)
Doctors giving you instructions that seem wrong	(0)	(1)	(2)	(3)	(4)
Doctors or nurses that have different ideas about health than you do	(0)	(1)	(2)	(3)	(4)

6. **Quality of Life:** We will now ask you about the quality of life for your child with a congenital heart defect.

**Please circle the number that corresponds to your response for each of the statements below.**

In general, would you say your child's health is...

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

**Because of my child's heart problem...**

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
He/she feels different from everybody in a bad way.	1	2	3	4	5
He/she can't do the physical activities he/she wants to do.	1	2	3	4	5
He/she misses too much school.	1	2	3	4	5
He/she feels guilty about the stress his/her heart disease	1	2	3	4	5
School work is difficult for him/her.	1	2	3	4	5
He/she gets unwanted attention.	1	2	3	4	5
He/she is afraid of medical procedures.	1	2	3	4	5
He/she tires easily.	1	2	3	4	5
He/she takes too much medicine.	1	2	3	4	5
Grown-ups around him/her are overprotective.	1	2	3	4	5
He/she feels sluggish.	1	2	3	4	5
He/she holds back when doing physical activities.	1	2	3	4	5
Other people are uncomfortable around him/her.	1	2	3	4	5
He/she is in pain.	1	2	3	4	5
He/she is likely to have other health problems.	1	2	3	4	5
He/she cannot wear what he/she wants.	1	2	3	4	5
He/she spends too much time dealing with his/her health.	1	2	3	4	5
He/she takes medicine that causes bad side effects.	1	2	3	4	5
His/her condition is likely to get worse.	1	2	3	4	5
He/she gets special treatment.	1	2	3	4	5
He/she misses social activities.	1	2	3	4	5
He/she is self-destructive.	1	2	3	4	5
He/she is afraid of dying.	1	2	3	4	5
It is difficult for him/her to get around from place to place.	1	2	3	4	5
He/she feels angry.	1	2	3	4	5
Other people treat him/her differently.	1	2	3	4	5
He/she looks different from everybody in a bad way.	1	2	3	4	5
He/she worries about his/her future.	1	2	3	4	5
He/she feels helpless.	1	2	3	4	5

### **Transition from pediatric to adult cardiology care:**

Children with congenital heart defects who receive care from a pediatric cardiology provider (a heart doctor who treats only children and adolescents) will eventually need to think about receiving care as adults. We are interested in learning about thoughts and concerns you may have about your child's transition from a pediatric cardiology provider to adult cardiology provider.

**Please circle the letter corresponding to your response to each question.**

7. Have you been told by doctors or other healthcare providers that your child will continue to need cardiac care or be seen by a cardiologist into adulthood?

- a) Yes
- b) No
- c) Unsure

8. Once your child becomes an adult, who do you think will provide his/her heart care?

- a) Cardiologist (heart doctor) → Continue to next question
- b) Primary care physician → Skip to question 10
- c) Don't know → Skip to question 10

9. Which type of cardiologist (heart doctor) would you expect to provide that care?

- a) Adult congenital heart disease specialist (heart doctor that treats adults born with congenital heart defects)
- b) Pediatric cardiologist (heart doctor that treats children only)
- c) General adult cardiologist (heart doctor that treats adults with any heart problem)
- d) Don't know

10. At what age (in years) do you expect your child to transition from a pediatric heart doctor to a heart doctor that treats adults?

11. Which of the following issues do you see as potential barriers to transitioning your child to a heart doctor that treats adults? (Select all that apply)

- a) Adult healthcare providers not understanding your child's medical condition
- b) Difficulty finding an appropriate adult healthcare provider
- c) Geographic distance from an adult healthcare provider is too far away
- d) Difficulty accessing appropriate health care insurance as an adult
- e) Health insurance payment/reimbursement issues from switching to a new/adult healthcare provider
- f) Replacing the strong relationship your child and family have with your current (pediatric) providers, clinic, and health team
- g) Your child's anxiety about receiving care from a different healthcare provider
- h) Other (please describe):

## Education and resources for adolescents with congenital heart defects:

In this section we will ask you a few questions that will help with the development of educational materials and resources for families of adolescents with congenital heart defects. These include questions about the technology that you use in your home, which may be used to deliver educational materials. **Please circle the letter corresponding to your response to each question.**

12. Do you have a computer (e.g. desktop, laptop, iPad, other tablet) with internet access at home?

- a) Yes
- b) No

13. Does your child with a congenital heart defect have access to a computer (e.g. desktop, laptop, iPad, other tablet) with internet access at home?

- a) Yes
- b) No

14. Do you have a cell phone?

- a) Yes → Continue to next question
- b) No → Skip to question 16

15. Which of the following capabilities does your cell phone have? (Select all that apply)

- a) Text/SMS
- b) Email access
- c) Internet access
- d) Applications/Apps
- e) Camera

16. Does your child with a congenital heart defect have his/her own cell phone?

- a) Yes → Continue to next question
- b) No → Skip to question 18

17. Which of the following capabilities does your child's phone have? (Select all that apply)

- a) Text/SMS
- b) Email access
- c) Internet access
- d) Applications/Apps
- e) Camera

18. As your child transitions from pediatric to adult cardiac care, what information or resources would be helpful for you to support your child?

19. How would you most like to receive educational materials or information about your child's transition to adult care? (Select all that apply)

- a) Written materials/brochures/handouts
- b) Electronic/internet-based materials
- c) In-person sessions with clinicians/providers
- d) In person groups with other families/patients
- e) Mobile applications
- f) Social media (Instagram, Facebook, Snapchat, etc)
- g) Other (please specify)

20. How do you think your child would most like to receive educational materials or information about his/her transition to adult care? (Select all that apply)

- a) Written materials/brochures/handouts
- b) Electronic/internet-based materials
- c) In-person sessions with clinicians/providers
- d) In person groups with other families/patients
- e) Mobile applications
- f) Social media (Instagram, Facebook, Snapchat, etc)
- g) Other (please specify)

21. Do you have other comments or concerns you would like to share about your child's transition from pediatric to adult cardiac care?

**Please take a moment to tell us a little about yourself as the person completing this survey.**

22. What is your relationship to the child with a congenital heart defect?

- a) Mother
- b) Father
- c) Legal guardian
- d) Other:

23. Please describe your living situation/marital status (select all that apply)

- a) Married/In a domestic partnership/Living with a partner
- b) Separated or divorced
- c) Single
- d) Widowed
- e) Other:

24. What is the highest degree or level of education you have completed?

- a) Completed some high school (or less)
- b) High school graduate, or equivalent (GED)
- c) Completed some college/Associate degree
- d) Completed college/4 year degree
- e) Trade/technical/vocational training
- f) Graduate degree (master's, professional, doctorate)

**Background information on your child with a congenital heart defect:**

**Now we will ask you to provide some background information about your child with a congenital heart defect.**

25. Is your child currently enrolled in school?

- a) Yes → Continue to next question
- b) No → Skip to question 30

26. What is your child's current grade in school (if your child is currently on summer break, what grade will your child be entering in the fall)?

- a) 4<sup>th</sup> grade
- b) 5<sup>th</sup> grade
- c) 6<sup>th</sup> grade
- d) 7<sup>th</sup> grade

- e) 8<sup>th</sup> grade
- f) 9<sup>th</sup> grade
- g) 10<sup>th</sup> grade
- h) 11<sup>th</sup> grade
- i) 12<sup>th</sup> grade
- j) Other (please specify):

27. What type of health insurance does your child have? (Select all that apply)
- a) Private commercial insurance (includes insurance purchased through Obamacare/Marketplace/Affordable Care Act)
  - b) Medicaid or CHIP
  - c) Military/CHAMPVA/TRICARE
  - d) Self-Pay/Uninsured
  - e) Other (please describe):

28. Is your child of Hispanic or Latino origin or descent?
- a) Yes, Hispanic or Latino
  - b) No, not Hispanic or Latino

29. How would you describe your child's race? (Select all that apply)
- a) American Indian/ Alaska Native
  - b) Asian
  - c) Black or African American
  - d) Native Hawaiian or Other Pacific Islander
  - e) White

30. Is your child male or female?
- a) Male
  - b) Female

***Thank you for taking the time to complete this survey. The information you have provided is will help us develop better resources for adolescents with congenital heart defects and their families.***