

Boston Children's Hospital
Pediatric Integrated Care Survey
For Parents/Guardians
Version 1.0



© 2015 Boston Children's Hospital
All Rights Reserved.

For permissions to use the Pediatric Integrated Care Survey, please contact
Dr. Richard Antonelli (Richard.Antonelli@childrens.harvard.edu)

Funded by a grant from
the Lucile Packard Foundation for Children's Health, Palo Alto, California

These first questions are about your child's health and health care needs.

1. In the past 12 months, has your child used medicine prescribed by a doctor, other than vitamins? *(Check ONE box)*
 - Yes
 - No
2. In the past 12 months, has your child needed to get special therapy such as physical, occupational, or speech therapy? *(Check ONE box)*
 - Yes
 - No
3. In the past 12 months, has your child had emotional, developmental, or behavioral problems for which he/she received treatment or counseling? *(Check ONE box)*
 - Yes
 - No
4. In the past 12 months, has your child needed medical equipment at home, such as equipment to help him/her breathe (ventilator, home oxygen, home nebulizer) or to help him/her feed (feeding tubes, feeding pumps), or to help him/her with mobility (wheel chairs, special bedding)? *(Check ONE box)*
 - Yes
 - No
5. In the past 12 months, was there a place where your child usually went when he/she needed routine preventive care, such as a physical exam or a well-child check-up? *(Check ONE box)*
 - Yes
 - No
6. In the past 12 months, do you think that your child experienced any of the following conditions? *(Check ALL boxes that apply)*
 - Behavioral Conditions (such as Attention Deficit, Depression, Anxiety, Conduct Problems)
 - Developmental Conditions (such as Autism, Autism Spectrum Disorder, Developmental Delay, Intellectual Disability)
 - Breathing Conditions (such as Asthma)
 - Neurological Conditions (such as Seizures, Head Injuries, Muscular Problems)
 - None

7. In the past 12 months, has your child used any of the following services? *(Check ALL boxes that apply)*
 - Mental Health Care or Counseling
 - Substance Abuse Treatment or Counseling
 - Home Health Care
 - Eyeglasses or Vision Care
 - Hearing Aids or Hearing Care
 - Mobility Aids or Devices
 - Communication Aids or Devices
 - None of these services
8. Is your child 3 years or older? *(Check ONE box)*
 - Yes → skip to question 10
 - No → go to question 9
9. In the past 12 months, has your child received Early Intervention Services? *(Check ONE box)*
 - Yes → Skip to question 11
 - No → Skip to question 11
10. In the past 12 months, has your child received Special Education Services? *(Check ONE box)*
 - Yes
 - No
11. In the past 12 months, how many times did your child visit a hospital emergency room? *(Check ONE box)*
 - Never
 - Once or twice
 - 3-5 times
 - 6 or more times
12. In the past 12 months, how many times did your child have an inpatient stay at the hospital? *(Check ONE box)*
 - Never
 - Once or twice
 - 3 or more times
13. In the past 12 months, did all of your child's medical providers have access to the same medical records? *(Check ONE box)*
 - Yes
 - No

14. In the past 12 months, has your child's health limited or prevented him/her in any way to do things that most children of the same age can do? (*Check ONE box*)

- Yes, definitely
- Yes, somewhat
- No

15. In the past 12 months, do you think that your child needed or used more medical care, mental health or educational services than is usual for most children of the same age? (*Check ONE box*)

- Yes, definitely
- Yes, somewhat
- No

16. In the past 12 months, how often have your child's health care needs changed? (*Check ONE box*)

- Changed all the time
- Changed frequently
- Changed once in a while
- Changed infrequently
- Have not changed

17. In the past 12 months, how often did you have difficulties or delays getting medical or social services for your child because there were waiting lists, backlogs, or other problems getting appointments? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

18. In the past 12 months, how often did you have difficulties or delays getting medical or social services for your child because you had trouble getting the information you needed? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

19. In the past 12 months, which of the following types of health care providers have contributed to your child's care? (*Check ALL boxes that apply*)

- Primary Care Provider/Pediatrician
- Medical and Surgical Specialty Providers
- Home Health Care Providers, such as At-Home Nurse, Personal Care Attendant
- School Health Care Providers, such as School Nurse, School Counselor
- Behavioral Health Care Providers, such as Psychiatrist, Psychologist, Counselor
- Therapists, such as Occupational, Speech, Physical
- Social Worker
- Complementary and Alternative Medicine Health Providers, such as Acupuncturist, Herbalist, Yoga Therapist
- Other

20. In the past 12 months, did your child see the following specialty providers? (*Check ALL boxes that apply*)
- Allergy/Immunology (relating to allergic conditions and immune system)
 - Cardiology (relating to the heart)
 - Dermatology (relating to skin)
 - Developmental Medicine (relating to behavior and development)
 - Endocrinology (relating to growth, hormones, including diabetes)
 - Gastroenterology (relating to the digestive system)
 - General Surgery (for procedures such as inserting feeding tubes, breathing tubes, other)
 - Genetics (relating to inherited conditions)
 - Gynecology (relating to the female reproductive system)
 - Hematology (relating to blood)
 - Nephrology (relating to the kidney)
 - Neurology (relating to seizures, headaches and muscles)
 - Neurosurgery (relating to brain and nerves)
 - Newborn Medicine (relating to care for newborns with special needs)
 - Nutrition (relating to feeding and growth)
 - Ophthalmology (relating to the eyes)
 - Otolaryngology (relating to ear, nose and throat)
 - Plastic Surgery (relating to surgeries such as cleft lip/cleft palate procedures)
 - Psychiatry (relating to behavior and mental health)
 - Pulmonology (relating to lungs and breathing)
 - Rheumatology (relating to joints, immune system)
 - Sports Medicine/Orthopedics (relating to musculoskeletal system)
 - Urology (relating to urinary tract, male reproductive system)

21. In the past 12 months, how many different health care providers have contributed to your child's care (including Primary Care Provider/Pediatrician, Medical and Surgical Specialty Providers, Home Health Care Providers, School Health Care Providers, Behavioral Health Care Providers, Therapists, Social Workers, Complementary and Alternative Medicine Health providers and any others) ? (*Check ONE box*)
- 2-5
 - 6-10
 - 11-15
 - 16-20
 - More than 20

The following questions refer to your child’s “care team.” When answering these questions, please consider all types of health care providers that you consider to be part of your child’s care team.

22. In the past 12 months, how often did your child’s care team members explain things in a way that you could understand? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

23. In the past 12 months, how often did you feel that your child’s care team members knew about the advice you got from your child’s other care team members? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

24. In the past 12 months, how often did you feel comfortable letting your child’s care team members know that you had any concerns about your child’s health or care? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not have any concerns

25. In the past 12 months, how often did you feel that your child’s care team members listened carefully to what you had to say about your child’s health and care? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

26. In the past 12 months, how often has someone on your child’s care team explained to you who was responsible for different parts of your child’s care? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

27. In the past 12 months, how often did you feel that your child’s care team members were aware of all tests and evaluations your child has had recently in order to avoid unnecessary testing? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I don’t know

28. In the past 12 months, how often did you feel that your child’s care team members followed through with their responsibilities related to your child’s care? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I don’t know

29. In the past 12 months, how often have you felt that your child’s care team members thought about the “big picture” when caring for your child, meaning dealing with all of your child’s needs? *(Check ONE box)*

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

30. In the past 12 months, have your child's care team members created short-term care goals, meaning goals up to 6 months in the future? (*Check ONE box*)

- Yes
- No

31. In the past 12 months, have your child's care team members created long-term care goals, meaning goals 6 months or longer into the future? (*Check ONE box*)

- Yes
- No

32. In the past 12 months, how often have your child's care team members treated you as a full partner in the care of your child? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

33. In the past 12 months, how often have your child's care team members talked with you about how health care decisions for your child will affect your whole family? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

34. In the past 12 months, how often have your child's care team members talked to you about things in your life that cause you stress because of your child's health or care needs? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

35. In the past 12 months, how often have your child's care team members talked to you about things that make it hard for you to take care of your child's health? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

36. In the past 12 months, how often have your child's care team members offered to communicate with you in ways other than an in-person visit, such as phone, email, skype or telehealth, if no physical examination was necessary? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

37. In the past 12 months, how often have your child's care team members offered you opportunities to connect with other families who they thought might be of help to you? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

This last set of questions asks information about you and your child.

38. What is your gender? (*Check ONE box*)

- Male
- Female

39. What is your relationship to the child who you answered questions about in this survey? (*Check ONE box*)

- Mother/Female Guardian
- Father/Male Guardian
- Other adult relative
- Other, specify:

40. What is the age of your child? (*Check ONE box*)

- Infant (less than 1 year old)
- 1 to 3 years old
- 4 to 12 years old
- 13 to 17 years old
- 18 years or older

41. What gender is your child? (*Check ONE box*)

- Male
- Female

42. What health insurance, if any, covers most or all of your child's medical care? (*Check ONE box*)

- Medicaid/Medicare
- Private/Commercial Insurance
- My child has no health insurance
- I don't know

43. Is your child Hispanic, Latino, or of Spanish origin? (*Check ONE box*)

- Yes
- No

44. Which of the following describes your child's racial or ethnic background? (*Check ONE box*)

- White or Caucasian
- Black or African-American
- Asian
- Native Hawaiian/Pacific Islander
- Native American/Alaskan Native
- Other

45. What is the primary language spoken at your home? (*Check ONE box*)

- English
- Spanish
- Chinese
- Tagalog
- Vietnamese
- French
- Korean
- German
- Arabic
- Russian
- Other

46. Counting yourself, how many adults over the age of 18 live in your home? (*Check ONE box*)

- 1
- 2
- 3
- 4
- 5+

47. How many children under the age of 18 live in your home? (*Check ONE box*)

- 0
- 1
- 2
- 3
- 4
- 5+

48. How many children under the age of 18 (not including the child that you answered the questions about in this survey) have special health care needs that require them to see multiple health care providers? (*Check ONE box*)

- 0
- 1
- 2
- 3
- 4
- 5+

Please feel free to write any comments in the free space below and on the next page:

