Pediatric Heart Network: Fontan Cross-Sectional Study

Form F007: Child Health Questionnaire – Parent Report

ENGSPANQ

A0. Was questionnaire completed in English or Spanish

#### <created var> CHQ Scoring Variables

ggh_item	<created var=""> Parent: Global Health (B1)</created>
pf_scale	<created var=""> Parent: Physical Functioning Domain (C1)</created>
reb_scale	<created var=""> Parent: Role/Social Limits - Emotional Domain (D1)</created>
rp_scale	<pre><created var=""> Parent: Role/Social Limits - Physical Domain (D2)</created></pre>
bp_scale	<created var=""> Parent: Bodily Pain Domain (E1, E2)</created>
be_scale	<created var=""> Parent: General Behavior Domain (F1, F2)</created>
gbe_item	<created var=""> Parent: Global Behavior (F2)</created>
mh_scale	<created var=""> Parent: Mental Health Domain (G1)</created>
se_scale	<created var=""> Parent: Self-Esteem Domain (H1)</created>
gh_scale	<created var=""> Parent: General Health Perceptions Domain (I1, B1)</created>
ch_item	<pre><created var=""> Parent: Change in Health (I2: reverse coded. See also COMP_HLTH)</created></pre>
pe_scale	<created var=""> Parent: Parental Impact - Emotional Domain (J1)</created>
pt_scale	<created var=""> Parent: Parental Impact - Time Domain (J2)</created>
fa_scale	<pre><created var=""> Parent: Family Activities (J3)</created></pre>
fc_item	<created var=""> Parent: Family Cohesion (J4)</created>
pf_z	<pre><created var=""> Parent: Physical Functioning Domain Z-Score</created></pre>
reb_z	<pre><created var=""> Parent: Role/Social Limits - Emotional Domain Z-Score</created></pre>
rp_z	<pre><created var=""> Parent: Role/Social Limits - Physical Domain Z-Score</created></pre>
bp_z	<created var=""> Parent: Bodily Pain Z-Score Domain</created>
be_z	<created var=""> Parent: General Behavior Domain Z-Score</created>
mh_z	<created var=""> Parent: Mental Health Domain Z-Score</created>
se_z	<created var=""> Parent: Self Esteem Domain Z-Score</created>
gh_z	<pre><created var=""> Parent: General Health Perceptions Domain Z-Score</created></pre>
pe_z	<created var=""> Parent: Parental Impact - Emotional Domain Z-Score</created>
pt_z	<pre><created var=""> Parent: Parental Impact - Time Domain Z-Score</created></pre>
PhS_raw	<pre><created var=""> Physical Summary Measure (raw score: weighted sum of z-scores)</created></pre>
PsS_raw	<pre><created var=""> Psychosocial Summary Measure (raw score: weighted sum of z- scores)</created></pre>
phs_score	<created var=""> Physical Summary Measure (norm-based score)</created>
pss_score	<created var=""> Psychosocial Summary Measure (norm-based score)</created>

## Section A: GENERAL INFORMATION

#### A1. Study identification number

Affix Study Label after questionnaire is completed.

# Replaced by blinded subject ID

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subj\_id Blinded subject ID

#### Blinded site ID <created var>

site_id	Blinded	site	ID	
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A2. Date of form completion

#### Replaced by age

	/	/		/			
Μ	М	D	D	Y	Υ	Y	Y

COMP_year	<create var=""></create>	Age of the	e child (yrs)	when A2.	form is compl	eted
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A3. Was the form completed during a study visit?

YES...... 1 NO......2

CMPVISIT A3. Was the form completed during a study visit?

# PARENT REPORT

# INSTRUCTIONS: USE THIS QUESTIONNAIRE FOR ALL PARENTS/PRIMARY CAREGIVERS OF CHILDREN 6 TO LESS THAN 19 YEARS OLD. This questionnaire asks about your child's health and well-being. Your individual answers will not be shared with anyone.

- 3. If you choose not to participate, it will not affect the care you receive.
- 4. Read each question carefully and mark the appropriate box that you feel most accurately represents your answer.
- 5. Certain questions may look alike, but each one is different. Some questions ask about problems your child may not have, but it's important for us to know that too. Please answer each question.
- 6. There are no right or wrong answers. If you are unsure how to answer a question, please give the best answer you can and make a comment in the margin.
- 7. All comments will be read, so please feel free to make as many as you wish.

# Section B: YOUR CHILD'S GLOBAL HEALTH

B1. In general, would you say your child's health is:

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	EXCELLENT 1
	VERY GOOD 2
	GOOD 3
	FAIR 4
	POOR 5
GEN_HLTH	B1. In general, would you say your child's health is

# Section C: YOUR CHILD'S PHYSICAL ACTIVITIES

The following questions ask about physical activities your child might do during a day.

C1. During the <u>past 4 weeks</u>, has your child been limited in any of the following activities due to <u>health problems</u>?

	YES, LIMITED A LOT	YES, LIMITED SOME	YES, LIMITED A LITTLE	NO, NOT LIMITED
a. Doing things that take <u>a lot</u> of energy, such as playing soccer or running?	1	2	3	4
b. Doing things that take <u>some</u> energy, such as riding a bike or skating?	1	2	3	4
c. Ability (physically) to get around the neighborhood, playground, or school?	1	2	3	4
d. Walking one block or climbing one flight of stairs?	1	2	3	4
e. Bending, lifting or stooping?	1	2	3	4
f. Taking care of him/herself, that is, eating, dressing, bathing, or going to the toilet?	1	2	3	4

LOTENERGY	C1a. Past 4 weeks: A lot of energy
SOMENERGY	C1b. Past 4 weeks: Some energy
GETAROUND	C1c. Past 4 weeks: Ability to get around
WALKING	C1d. Past 4 weeks: Walking
BENDING	C1e. Past 4 weeks: Bending
TAKINGCARE	C1f. Past 4 weeks: Taking care

# Section D: YOUR CHILD'S EVERYDAY ACTIVITIES

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These questions ask if your child's school work or activities with friends may or may not have been limited over the <u>past 4 weeks</u>.

D1. During the <u>past 4 weeks</u>, has your child's school work or activities with friends been limited in any of the following ways due to EMOTIONAL difficulties or problems with his/her BEHAVIOR?

	YES, LIMITED A LOT	YES, LIMITED SOME	YES, LIMITED A LITTLE	NO, NOT LIMITED
a. Limited in the KIND of schoolwork or activities with friends he/she could do	1	2	3	4
b. Limited in the AMOUNT of time he/she could spend on schoolwork or activities with friends	1	2	3	4
c. Limited in PERFORMING schoolwork or activities with friends (it took extra effort)	1	2	3	4

KIND_EMOTN	D1a. Emotional activities: Kind of schoolwork
AMNT_EMOTN	D1b. Emotional activities: Amount of time on schoolwork
PRFORM_EMOTN	D1c. Emotional activities: Performing schoolwork

D2. During the <u>past 4 weeks</u>, has your child's school work or activities with friends been limited in any of the following ways due to problems with his/her PHYSICAL health?

	YES, LIMITED A LOT	YES, LIMITED SOME	YES, LIMITED A LITTLE	NO, NOT LIMITED
a. Limited in the KIND of schoolwork or activities with friends he/she could do	1	2	3	4
b. Limited in the AMOUNT of time he/she could spend on schoolwork or activities with friends	1	2	3	4

KIND_PHYS	D2a. Physical health : kind of schoolwork
AMNT_PHYS	D2b. Physical health : amount of schoolwork

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# Section E: PAIN

These questions ask about any physical pain or discomfort your child may have experienced in the <u>past 4 weeks</u>.

E1. During the past 4 weeks, HOW MUCH bodily pain or discomfort has your child had?

 NONE
 1

 VERY MILD
 2

 MILD
 3

 MODERATE
 4

 SEVERE
 5

 VERY SEVERE
 6

HMUCH\_PAIN E1. How much bodily pain

E2. During the past 4 weeks, HOW OFTEN has your child had bodily pain or discomfort?

NONE OF THE TIME1					
O	ICE OR TWICE2				
AI	FEW TIMES3				
FAIRLY OFTEN4					
VERY OFTEN5					
EVERY/ALMOST EVERY DAY6					
HOFTEN_PAIN	E2. How often has child had bodily pain				

# Section F: BEHAVIOR

Below is a list of items that describe children's behavior or problems they sometimes have. Please read each statement and choose the answer that best describes how often your child acted that way.

F1. How often during the past 4 weeks did each of the following statements describe your child?

	VERY OFTEN	FAIRLY OFTEN	SOME- TIMES	ALMOST NEVER	NEVER
a. Argued a lot	1	2	3	4	5
b. Had difficulty concentrating or paying attention	1	2	3	4	5
c. Lied or cheated	1	2	3	4	5
d. Stole things inside or outside the home	1	2	3	4	5

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e. Had tantrums or a hot temper	1	2	3	4	5
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ARGUED	F1a. Describe your child: argued a lot
DIF_CONCNT	F1b. Describe your child: difficulty concentrating
LIED	F1c. Describe your child: lied or cheated
STOLE	F1d. Describe your child: stole things
TANTRUMS	F1e. Describe your child: had tantrums

F2. Compared to other children your child's age, in general would you say his/her behavior is

EXCELLENT	1
VERY GOOD	2
GOOD	3
FAIR	4
POOR	5

GEN\_BEHAVR F2. General behavior

# Section G: WELL-BEING

The following phrases are about children's moods. Please read each item and tell us how often over the <u>past 4 weeks</u> you think your child felt or acted this way.

G1.	How much of the time during the past 4 weeks, do you think your child	
-----	---	--

	ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME
a. Felt like crying?	1	2	3	4	5
b. Felt lonely?	1	2	3	4	5
c. Acted nervous?	1	2	3	4	5
d. Acted bothered or upset?	1	2	3	4	5
e. Acted cheerful?	1	2	3	4	5

CRYING	G1a. Do you think your child: felt like crying
LONELY	G1b. Do you think your child: felt lonely
NERVOUS	G1c. Do you think your child: felt nervous
UPSET	G1d. Do you think your child: upset
CHEERFUL	G1e. Do you think your child: cheerful

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# Section H: SELF-ESTEEM

The following questions ask about your child's satisfaction with self, school, and others. It may be helpful if you keep in mind how other children your child's age might feel about these areas.

H1. During the past 4 weeks, how satisfied do you think your child has felt	about
---	-------

	VERY SATISFIED	SOMEWHAT SATISFIED	NEITHER SATISFIED NOR DIS- SATISFIED	SOMEWHAT DIS- SATISFIED	VERY DIS- SATISFIED
a. His/her school ability?	1	2	3	4	5
b. His/her athletic ability?	1	2	3	4	5
c. His/her friendships?	1	2	3	4	5
d. His/her looks/appearance?	1	2	3	4	5
e. His/her family relationships?	1	2	3	4	5
f. His/her life overall?	1	2	3	4	5

SCHOOL	H1a. How satisfied: school ability
ATHLETIC	H1b. How satisfied: athletic ability
FRIENDSHIP	H1c. How satisfied: friendships
APPERANCE	H1d. How satisfied: appearance
FAMRELATN	H1e. How satisfied: family relationships
LIFEOVERALL	H1f. How satisfied: life overall

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# Section I: YOUR CHILD'S HEALTH

The following statements are about health in general. Please choose one answer that best describes how true or false each statement is about your child.

<ol> <li>How true or false are each of these statements for your child</li> </ol>
---

	DEFINITELY TRUE	MOSTLY TRUE	DON'T KNOW	MOSTLY FALSE	DEFINITELY FALSE
a. My child seems to be less healthy than other children I know.	1	2	3	4	5
b. My child has never been seriously ill.	1	2	3	4	5
c. When there is something going around my child usually catches it.	1	2	3	4	5
d. I expect my child will have a very healthy life.	1	2	3	4	5
e. I worry about my child's health more than other people worry about their children's health.	1	2	3	4	5

LESSHAPPY	I1a. True or false: child is less healthy
NEVERILL	I1b. True or false: child has never been seriously ill
CATCHES	I1c. True or false: child usually catches it
HEALTHYLIFE	I1d. True or false: child will have healthy life
WORRY	I1e. True or false: worry about my child's health

12. Compared to one year ago, how would you rate your child's health now?

MUCH BETTER NOW THAN 1 YEAR AGO1	I
SOMEWHAT BETTER NOW THAN 1 YEAR AGO2	2
ABOUT THE SAME NOW AS 1 YEAR AGO	3
SOMEWHAT WORSE NOW THAN 1 YEAR AGO4	1
MUCH WORSE NOW THAN 1 YEAR AGO	5

COMP\_HLTH I2. Compared to a year ago, rate child's health

# Section J: YOU AND YOUR FAMILY

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These next questions are about how your child's health may affect you and your family.

J1. During the <u>past 4 weeks</u>, how MUCH emotional worry or concern did each of the following cause YOU?

	NONE AT ALL	A LITTLE BIT	SOME	QUITE A BIT	A LOT
a. Your child's physical health	1	2	3	4	5
b. Your child's emotional well-being or behavior	1	2	3	4	5
c. Your child's attention or learning abilities	1	2	3	4	5

WRY_PHYHLTH	J1a. How much worry: child's physical health
WRY_EMTWELL	J1b. How much worry: child's emotional health
WRY_ATTENT	J1c. How much worry: child's learning abilities

J2. During the <u>past 4 weeks</u>, were you LIMITED in the amount of time YOU had for your own needs because of

	YES, LIMITED A LOT	YES, LIMITED SOME	YES, LIMITED A LITTLE	NO, NOT LIMITED
a. Your child's physical health?	1	2	3	4
b. Your child's emotional well-being or behavior?	1	2	3	4
c. Your child's attention or learning abilities?	1	2	3	4

LIM_PHYHLTH	J2a. Limited in time: child's physical health
LIM_EMTWELL	J2b. Limited in time: child's emotional well-being
LIM_ATTENT	J2c. Limited in time: child's attention

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### J3. During the past 4 weeks, HOW OFTEN has your child's health or behavior

	VERY OFTEN	FAIRLY OFTEN	SOME- TIMES	ALMOST NEVER	NEVER
a. Limited the types of activities you could do as a family?	1	2	3	4	5
<ul> <li>b. Interrupted various everyday family activities (eating meals, watching TV)?</li> </ul>	1	2	3	4	5
c. Limited your ability as a family to "pick up and go" on a moment's notice?	1	2	3	4	5
d. Caused tension or conflict in your home?	1	2	3	4	5
e. Been a source of disagreements or arguments in your family?	1	2	3	4	5
f. Caused you to cancel or change plans (personal or work) at the last minute?	1	2	3	4	5

OFN_ACTVTY	J3a. How often has child's health:limited family activities
OFN_DAILYACT	J3b. How often has child's health:interrupted family activities
OFN_PICKUP	J3c. How often has child's health:limited ability 'get up and go'
OFN_TENSION	J3d. How often has child's health:caused tension
OFN_ARGUMNT	J3e. How often has child's health:been source of arguements
OFN_CANCEL	J3f. How often has child's health: caused you to cancel plans

J4. Sometimes families may have difficulty getting along with one another. They do not always agree and they may get angry. In general, how would you rate your family's ability to get along with one another?

EXCELLENT1	
VERY GOOD2	
GOOD3	
FAIR4	
POOR5	

GETALONG J4. How would you rate your family's ability to get along

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	Section K: FACTS ABOUT YOUR CHILD
This	section asks some general questions about your child and his or her education and health.
K1	Is your child MALE1 FEMALE2
•	
	GENDER K1. Is your child
K2	Was this your first child (biological or adopted?)
	YES1 NO2
	FIRSTBORN K2. Was this your first child
K3	
	What is your child's date of birth? / / / /
Remo	wed to protect privacy
K4	
κ4	What is the <u>highest</u> grade of school your child has <u>completed</u> ? (Check one grade only)
	PRESCHOOL 1
	KINDERGARTEN 2
	1 <sup>ST</sup> GRADE
	2 <sup>ND</sup> GRADE 4
	3 <sup>RD</sup> GRADE5
	4 <sup>™</sup> GRADE6
	5 <sup>™</sup> GRADE7
	6 <sup>TH</sup> GRADE
	7 <sup>TH</sup> GRADE
	8 <sup>TH</sup> GRADE10
	9 <sup>™</sup> GRADE11
	10 <sup>™</sup> GRADE12
	11 <sup>™</sup> GRADE13
	12 <sup>™</sup> GRADE14
	13 <sup>™</sup> GRADE15
	UNGRADED
	a. If UNGRADED, how many years attended? years
	EDUCATN K4. What is the highest grade of education
	LUCCAIN NA. WHAT IS THE HIGHEST GLAUE OF EUUCACION

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EDU\_YR K4a. If ungraded, how many years

K5 Have you ever been told by a teacher, school official, doctor, nurse, or other health professional that your child has any of the following conditions?

	YES	NO
a. Anxiety problems	1	2
b. Asthma	1	2
c. Attention problems	1	2
d. Behavioral problems	1	2
e. Chronic allergies or sinus trouble	1	2
f. Chronic orthopedic, bone or joint problems	1	2
g. Chronic respiratory, lung or breathing problems (NOT ASTHMA)	1	2
h. Chronic rheumatic disease	1	2
i. Depression	1	2
j. Developmental delay or mental retardation	1	2
k. Diabetes	1	2
I. Epilepsy (seizure disorder)	1	2
m. Hearing impairment or deafness	1	2
n. Learning problems	1	2
o. Sleep disturbance	1	2
p. Speech problems	1	2
q. Vision problems	1	2

ANXIETY	K5a. Anxiety problems
ASTHMA	K5b. Asthma
ATTENT_PROB	K5c. Attention problems
BEHAV_PROB	K5d. Behavioral problems
ALLERGY	K5e. Chronic allergies
ORTHOP_PROB	K5f. Orthopedic problems

RESPIR_PROB	K5g. Respiratory problems
RHEUMAT	K5h. Rheumatic disease
DEPRESSION	K5i. Depression
RETARD	K5j. Retardation
DIABETES	K5k. Diabetes
EPILEPSY	K51. Epilepsy
DEAFNESS	K5m. Deafness
LEARN_PROB	K5n. Learning problems
SLEEP_PROB	K5o. Sleeping problems
SPEECH_PROB	K5p. Speech problems
VISION_PROB	K5q. Vision problems

r. Does your child have any other chronic medical condition that is affecting what they do or how they feel?

If YES, please describe below.

YES1	
NO2	2

MEDCOND	K5r. Any other medical condition?
MEDCOND_SP	K5ri. Any other medical condition: specify

K6 Which of the following best describes your child's racial background?

WHITE 1	
BLACK OR AFRICAN AMERICAN	2
ASIAN	5
AMERICAN INDIAN OR ALASKAN NATIVE 4	-
NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER 5	,
MORE THAN ONE RACE 6	,
a. Specify	
OTHER	)
b. Specify	
DO NOT WISH TO PROVIDE7	7
UNKNOWNE	3

CHLDRACE	K6. Which describes your child's racial background
CHLDMORE	K6a. More than one race: specify
CHLDOTHR	K6b. Other: specify

.

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K7	Is your child	d of Hispanic o	or Latino origin?		
	YES	1	NO2	DO NOT WISH TO PROVIDE	
	CHLDHISP	K7. Is your	child of Hispanic or	Latino origin	

1.01

# Section L: FACTS ABOUT YOU

This section asks some general questions about you. We are interested in learning about the caregivers of patients as well as the patients themselves. Please remember all information is confidential.

CARE\_age <create var> Age of the parent (yrs) when L2. his/her child was born

L3. Which of the following best describes your current work status?

	YES	NO
a. Not working due to my child's health	1	2
b. Not working for other reasons	1	2
c. Looking for work outside the home	1	2
d. Working full or part time (either outside the home or at a home-based business)	1	2
e. Full-time homemaker	1	2

NOWRK_CHILD	L3a. Work: Not working due to child's health
NOWRK_OTHER	L3b. Work: Other reason
LOOKWRK	L3c. Work: Looking
WORKS	L3d. Work: Full or part time
HOMEMAKER	L3e. Work: Full time homemaker

L4. Which of the following best describes your relationship to your child?

BIOLOGICAL PARENT	.1
STEP PARENT	.2
FOSTER PARENT	.3
ADOPTIVE PARENT	.4
GUARDIAN	.5
OTHER	.99
a. If OTHER, please specify	

CARE_RELATN	L4. Which describes relationship
RELATN_SP	L4a. Relationship: specify

L5. What is the highest grade of school that you have completed?

SOME HIGH SCHOOL OR LESS	1
HIGH SCHOOL GRADUATE OR GED	2
VOCATIONAL SCHOOL, SOME COLLEGE OR 2 YEAR DEGREE	3
4 YEAR COLLEGE GRADUATE	4
GRADUATE DEGREE	5

CARE\_EDU L5. Highest grade of school completed

L6. Which of the following best describes your current marital status?

MARRIED	. 1
WIDOWED	.2
DIVORCED	. 3
SEPARATED	. 4
REMARRIED	. 5
NEVER MARRIED	. 6
OTHER	.99
a. If OTHER, please specify	/

CARE_MARITL	L6. Marital status
MARITL_SP	L6a. Other, specify

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L7. Which of the following best describes your racial background?

WHITE 1
AFRICAN-AMERICAN 2
HISPANIC 3
ASIAN/PACIFIC ISLANDER 4
DO NOT WISH TO PROVIDE7
OTHER99
a. If OTHER, please specify

CARE_RACE	L7. Racial background	
CARER_SP	L7a. Specify racial background	

L8. Which of the following categories best represents the combined income for all family members in your household added together for the past 12 months?

< \$20,000	. 1
\$20,000 - 39,000	. 2
\$40,000 - 59,000	. 3
\$60,000 - 79,000	. 4
\$80,000 - 99,000	. 5
> \$100,000	. 6
DO NOT WISH TO PROVIDE	-7

FAMINCME L8. Household income

L9. Did you require physical assistance to circle the responses to questions on this form?

YES	1
NO	2

NDASSIST L9. Did you require physical assistance

# THANK YOU FOR YOUR PARTICIPATION!

FORMSTAT_ID	Unique form/subject ID		
FORM_ID	4 letter code for the form		
VER_ID	1 letter code added to form code to make unique form/version		
DESTATUS	Form completion		

#### **END OF FORM**

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