

**Section A: KEY IDENTIFYING INFORMATION**

ENGSPANQ	A0. Was questionnaire completed in English or Spanish?
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**CHAT Domain Variables**

activities	<created var> CHAT Domain: Activity Limitations (6 items: D1a-f)
emotions	<created var> CHAT Domain: Emotional Concerns (8 items: D2a-c, E2a, G1a-d)
friends	<created var> CHAT Domain: Friendship Problems (3 items: E1a-c)
jobs	<created var> CHAT Domain: Career Concerns (5 items: F1a-b, F2a-c)
discomfort	<created var> CHAT Domain: Symptom Discomfort (10 items: C2a-d,f; C3a-d,f)

A1. Study Identification Number \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Affix Study Label after questionnaire is completed.

*Replaced by blinded subject ID*

subj_id	Blinded subject ID
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*Blinded site ID <created var>*

site_id	Blinded site ID
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A2. Date of form completion \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
M M D D Y Y Y Y

*Replaced by age*

COMP_AGE	<created var> Age of the subject (yrs) at A2. Date of form completion
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A3. Was the form completed during a study visit? YES..... 1  
NO..... 2

COMP_SV	A3. Was the form completed during a study visit?
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enroll_age	<created var> Age (yrs) at enrollment: enrollment date (F02B, A3) - DOB (F02A, A3)
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**INSTRUCTIONS:**

Thank you for completing the following questionnaire. Your answers will help us to understand quality of life in older children and teenagers with a heart condition.

The questions below ask about how your heart condition affects you, your ability to do physical exercise, your family, and your social life. There are no right or wrong answers; we are interested in how your heart condition affects you.

**Please circle** the answer that is right for you. Because people of different ages will complete the questionnaire, some questions may not apply to you. However, **please try to answer all the questions.**

Example: What is Bugs Bunny's favorite food?

<b>Cabbage</b>	<b>Spinach</b>	<b>Potatoes</b>	<b>Carrots</b>	<b>Tomatoes</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

**Section B: FACTS ABOUT YOU**

B1. What is the highest grade of school that you have completed? (Check one grade only)

GRADE 4 ..... 6

GRADE 5 ..... 7

GRADE 6 ..... 8

GRADE 7 ..... 9

GRADE 8 ..... 10

GRADE 9 ..... 11

GRADE 10 ..... 12

GRADE 11 ..... 13

GRADE 12 ..... 14

GRADE 13 ..... 15

COLLEGE ..... 16

UNIVERSITY ..... 17

NOT IN SCHOOL, COLLEGE, OR UNIVERSITY ..... -1

EDU\_LEVEL

B1. Education level

B2. Do you have a job outside your home during the year for which you get paid?

NOT EMPLOYED ..... 1

PART TIME JOB ..... 2

SUMMER JOB ONLY ..... 3

FULL-TIME JOB ..... 4

JOB

B2. Do you have a job outside your home

**Section C: SYMPTOMS OF HEART CONDITION**

The following questions ask about what discomforts or symptoms you have because of your heart condition. For all the following questions please circle the answer that is right for you.

C1. In general how would you say your health is?

EXCELLENT ..... 1

VERY GOOD ..... 2

GOOD ..... 3

FAIR ..... 4

POOR ..... 5

GEN\_HLTH

CHAT Domain: C1. In general, how would you say your health is?

C2. **Over the last month**, how often did you have each of the discomforts or symptoms shown in the table?

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
a. Chest pain, or chest tightness, or chest discomfort	0	1	2	3	4
b. Palpitations (fast heart beats)	0	1	2	3	4
c. Shortness of breath	0	1	2	3	4
d. Dizziness, or feeling faint	0	1	2	3	4
e. Becoming blue (cyanosed)	0	1	2	3	4
f. Tiredness	0	1	2	3	4

CHSTPAINOFT	C2a. How often: chest pain
PALPITOFT	C2b. How often: palpitations
SHORTBRTHOFT	C2c. How often: shortness of breath
DIZZYOFT	C2d. How often: dizziness
CYANOSEDFT	C2e. How often: becoming blue
TIREDOFT	C2f. How often: tiredness

C3. **Over the last month**, how strong/intense were each of these discomforts or symptoms?

	NEVER	MILD	MODERATE	SEVERE
a. Chest pain, or chest tightness, or chest discomfort	0	1	2	3
b. Palpitations (fast heart beats)	0	1	2	3
c. Shortness of breath	0	1	2	3
d. Dizziness, or feeling faint	0	1	2	3
e. Becoming blue (cyanosed)	0	1	2	3
f. Tiredness	0	1	2	3

CHSTPAININT	C3a. How intense: chest pain
PALPITINT	C3b. How intense: palpitations
SHORTBRTHINT	C3c. How intense: shortness of breath
DIZZYINT	C3d. How intense: dizziness
CYANOSEDINT	C3e. How intense: becoming blue
TIREDEINT	C3f. How intense: tiredness

- C4. If you have any other discomforts or symptoms caused by your heart condition please write them in the space below.

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OTH\_SYMPT

C4. If you have any other discomforts, please write them below

- C5. Do you take any medications for your heart condition?

YES .....1      NO .....2 (**GO TO D1**)

MED\_HEART

C5. Do you take any medications for your heart condition

C6. If you take any medicines for your heart condition.....

DO YOUR HEART MEDICINES EVER...	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
a. Make you feel weak, or tired, or nauseous, or dizzy, or give you cramps?	0	1	2	3	4
b. Give you side-effects that interfere with your daily activities?	0	1	2	3	4

MED_DIZZY	C6a. Heart medicines ever: make you dizzy
MED_SIDEFF	C6b. Heart medicines ever: give you side-effects

### Section D: PHYSICAL ACTIVITIES

The following questions ask about how your heart condition affects your ability to do physical things/activities.

D1. How often does your heart condition stop you from doing any of the following?

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
a. Vigorous activity like running/gym/lifting heavy objects	0	1	2	3	4
b. Moderate activity like dancing/shopping and carrying	0	1	2	3	4
c. Light activity like walking	0	1	2	3	4
d. Washing/bathing yourself	0	1	2	3	4
e. Going to places you would like to visit	0	1	2	3	4
f. Taking part in hobbies you would like to do	0	1	2	3	4

RUNNING	D1a. How often does condition stop you from: running
DANCING	D1b. How often does condition stop you from: dancing
WALKING	D1c. How often does condition stop you from: walking
WASHING	D1d. How often does condition stop you from: washing
GOING	D1e. How often does condition stop you from: going
HOBBIES	D1f. How often does condition stop you from: hobbies

D2. How often do you experience the following?

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
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a. When doing any exercise, do you ever get worried of doing too much because of your heart condition?	0	1	2	3	4
b. How often have you felt upset by not being able to do as much exercise as you really want to?	0	1	2	3	4
c. Do other people ever stop you from doing exercises because of your heart condition?	0	1	2	3	4

WOORY_EX	D2a. How often do you experience: worry
UPSET_EX	D2b. How often do you experience: upset
STOPYOU_EX	D2c. How often do you experience: people stop you

### Section E: RELATIONSHIPS

The following questions ask about how your heart condition affects your relationship with friends.

E1. Does your heart condition ever stop you from.....

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
a. Having more friends?	0	1	2	3	4
b. Getting along better with your friends?	0	1	2	3	4
c. Going out more with your friends, or doing more things with your friends?	0	1	2	3	4

HAVE_FRND	E1a. Does your heart condition ever stop you from: having friends
GET_ALONG	E1b. Does your heart condition ever stop you from: going out
GOING_OUT	E1c. Does your heart condition ever stop you from: getting along

E2. Because of your heart condition.....

	NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	VERY MUCH
a. Do you FEEL DIFFERENT from other people your age?	0	1	2	3	4
b. Has your SOCIAL LIFE been affected?	0	1	2	3	4

FEEL_DIFF	E2a. Because of your heart condition: feel different
SOC_LIFE	CHAT Domain: E2b. Has your social life been affected?

**Section F: SCHOOL/WORK**

The following questions ask about how your heart condition affects you in school or at work.

F1. Do you think that your heart condition.....

	NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	VERY MUCH
a. Would make it harder for you to get into any colleges, universities or jobs that you would have liked?	0	1	2	3	4
b. Makes it harder for you to get better grades at school, college or university, or do better at your job?	0	1	2	3	4

GET_JOB	F1a. Do you think your heart condition: hard to get a job
GET_GRADES	F1b. Do you think your heart condition: hard to get good grades



F2. How often do the following happen to you?

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
a. Miss school, college, university or work because of your heart condition?	0	1	2	3	4
b. Wish people at work or school were more understanding of your heart condition?	0	1	2	3	4
c. Worry that your heart condition may stop you from doing certain jobs or careers in the future?	0	1	2	3	4

MISS_SCHL	F2a. How often: miss school
UNDERSTAND	F2b. How often: understand
WORRY_FUT	F2c. How often: worry about future

### Section G: CONCERNS ABOUT HEART CONDITION

The following questions ask about concerns you may have about your heart condition.

G1. How often do you.....

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
a. Get worried or sad about your heart condition?	0	1	2	3	4
b. Worry that your heart may stop beating?	0	1	2	3	4
c. Get worried of your heart condition getting worse?	0	1	2	3	4
d. Get worried of having to have an operation on your heart in the future?	0	1	2	3	4

SAD_HC	G1a. How often do you: get sad
WORRY_HC	G1b. How often do you: worry
WORSE_HC	G1c. How often do you: get worse
OPER_HC	G1d. How often do you: operation

G2. On a scale of 1 to 5, how serious do you think your condition is?

Please circle the number that is right for you.

0	1	2	3	4	5
CHAT Questionnaire	Form F009	Version A: 08-20-02	Page 9 of 10		

NOT AT  
ALL  
SERIOUS

VERY  
SERIOUS

SC_COND	CHAT Domain: G2. How serious do you think your condition is?
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<b>Section H: FORM COMPLETION</b>
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H1. Did you require physical assistance to circle the responses to questions on this form?

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

CHATHELP	H1. Did you require physical assistance to circle responses
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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