

SUPPLEMENTAL MATERIAL

Table S1. Domains and corresponding item numbers.

Domain	Item numbers
Physical Limitations	4, 5, 31, 32, 33
Symptoms	1, 2, 6, 8, 9
Arrhythmia	3, 7, 10
Quality of Life	11, 12, 26, 27, 28, 29, 30
Anxiety/Depression	13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25

Table S2. Other significant medical diagnoses.

Diabetes	Hypertension	Chronic obstructive pulmonary disease/Asthma	Coronary artery disease	Arrhythmia
9 (8.7%)	16 (15.5%)	11 (10.7%)	0 (0%)	1 (1%)

Figure S1. The following questions refer to **congenital heart disease** and how it may affect your life. Please read and complete the following questions. There are no right or wrong answers. Please mark the answer that best applies to you.

1. **Congenital heart disease** affects people in a variety of ways. Please indicate how often you have experienced the following symptoms over the past two weeks.

Symptom	All of the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once a week	Never over the past two weeks
Felt dizzy	0	0	0	0	0	0	0
Had a headache	0	0	0	0	0	0	0
Felt like you were about to faint or fainted	0	0	0	0	0	0	0
Felt that you could not catch your breath	0	0	0	0	0	0	0
Felt your energy level was low	0	0	0	0	0	0	0
Felt as if you could fall asleep anywhere at any time	0	0	0	0	0	0	0
Felt that your heart was racing	0	0	0	0	0	0	0

2. Over the past two weeks how much has **swelling** in your legs, abdomen, or hands bothered you?

Extremely	Quite a lot	Moderately	Slightly	Not at all	I've had no swelling
0	0	0	0	0	0

3. Compared with two weeks ago, have symptoms related to your **congenital heart disease** changed? My symptoms have become...

Much worse	Slightly worse	Not changed	Slightly better	Much better	I've had no symptoms over the last two weeks
0	0	0	0	0	0

4. Compared with two weeks ago, has there been a change in the amount of time that you have felt your heart was **in an abnormal rhythm**? My heart has been in an **abnormal rhythm**...

Much more often	Slightly more often	The same amount of the time	Less often	Much less often	Never over the last two weeks
0	0	0	0	0	0

5. Over the past two weeks how often have you held back from doing something because you were afraid that something bad might happen as a result of your **congenital heart disease**?

All of the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once a week	Never over the past two weeks
0	0	0	0	0	0	0

6. Over the past two weeks have you felt that your quality of life has gotten worse because of your **congenital heart disease**?

I felt that way all the time	I felt that way most of the time	I occasionally felt that way	I rarely felt that way	I never felt that way
0	0	0	0	0

7. Over the past two weeks have you felt that your **congenital heart disease** defined who you are?

I felt that way all the time	I felt that way most of the time	I occasionally felt that way	I rarely felt that way	I never felt that way
0	0	0	0	0

8. Over the past two weeks have you felt that your **congenital heart disease** made you different from everyone else?

I felt that way all the time	I felt that way most of the time	I occasionally felt that way	I rarely felt that way	I never felt that way
0	0	0	0	0

9. Over the past two weeks have you felt that people have treated you differently as a result of your **congenital heart disease**?

I felt that way all the time	I felt that way most of the time	I occasionally felt that way	I rarely felt that way	I never felt that way
0	0	0	0	0

10. How does living with **congenital heart disease** can affect you psychologically? Over the past two weeks I have felt...

	All the time	Most of the time	Occasionally	Rarely	Never
Depressed	0	0	0	0	0
Isolated	0	0	0	0	0
A lack of interest in life	0	0	0	0	0
Like something bad might happen to me as a result of my congenital heart disease	0	0	0	0	0
Anxiety about needing surgery	0	0	0	0	0
As if nothing is going to work to help my congenital heart disease	0	0	0	0	0
As if something new was going wrong with my heart	0	0	0	0	0

11. Patients with **congenital heart disease** frequently experience difficulties with sleeping. Over the past two weeks when I was trying to fall asleep, I...

	All of the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once a week	Never over the past two weeks
Felt like my thoughts were racing	0	0	0	0	0	0	0
Felt afraid that I might not wake up	0	0	0	0	0	0	0

when I fall
asleep

Wondered
what my
heart was
doing

0 0 0 0 0 0 0

12. How much does your **congenital heart disease** affect your life? Over the past two weeks, my heart disease...

Definitely Somewhat Slightly Not at all Does not apply

Made it difficult for
me to concentrate on
other parts of my life

0 0 0 0 0

Made me feel that I
had to arrange my
life around my heart
disease

0 0 0 0 0

Directed my plans for
the future

0 0 0 0 0

Made me experience
guilt that I am a
burden on my family

0 0 0 0 0

Made me concerned
that I might not have
a successful career
because of my health

0 0 0 0 0

Made me feel short
of breath when
walking up a flight of
stairs

0 0 0 0 0

Made me feel like
everything was an
absolute struggle

0 0 0 0 0

Made me not want to
do even routine
things (like getting
dressed, showering,
or making breakfast)

0 0 0 0 0

Figure S2.

Since your previous visit with your cardiologist has there been an overall change in your heart disease that affects the way you feel? Would you say that you are worse, about the same, or better? (Circle the numbers that apply)	
1) Worse (Go to series A) 2) About the same (Done) 3) Better (Go to series B)	
<p style="text-align: center;"><u>Series A</u></p> <p>How much more limited would you say you have been due to heart disease since the last time the doctor saw you?</p> <ol style="list-style-type: none">1) Almost the same, hardly limited, not important2) A little more limited, but large enough to be important3) Somewhat more limited but large enough to be important4) Moderately more limited, an important change for the worse5) A good deal more limited, an important change for the worse6) A great deal more limited, a very important change for the worse7) A very great deal more limited, a very important change for the worse	<p style="text-align: center;"><u>Series B</u></p> <p>How much better would you say you have been due to heart disease since the last time the doctor saw you?</p> <ol style="list-style-type: none">1) Almost the same, slightly less limited, not important2) A little less limited, but large enough to be important3) Somewhat less limited but large enough to be important4) Moderately less limited, an important change for the better5) A good deal less limited, an important change for the better6) A great deal less limited, a very important change for the better7) A very great deal less limited, a very important change for the better