Quality Of Life And Care

Research Subject ID Research ID _____

Quality of Life Enjoyment and Satisfaction Questionnaire - Short Form (Q-LES-Q-SF)

Would you say that in general your health is	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor ◯ Don't know/Not sure ◯ Refused
Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?	_____
Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?	◯ None ◯ Don't know/Not sure ◯ Refused
Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?	_____
Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?	◯ None ◯ Don't know/Not sure ◯ Refused
During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?	_____
During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?	◯ None ◯ Don't know/Not sure ◯ Refused

PROMIS© Version 1.1 Pediatric Profile 25

	With no trouble	With a little trouble	With some trouble	With a lot of trouble	Not able to do
In the past 7 days I could do sports and exercise that other kids my age could do	◯	◯	◯	◯	◯

In the past 7 days I could get up from the floor	◯ 4 - With no trouble ◯ 3 - With a little trouble ◯ 2 - With some trouble ◯ 1 - With a lot of trouble ◯ 0 - Not able to do
In the past 7 days I could walk up stairs without holding on to anything	◯ 4 - With no trouble ◯ 3 - With a little trouble ◯ 2 - With some trouble ◯ 1 - With a lot of trouble ◯ 0 - Not able to do
In the past 7 days I have been physically able to do the activities I enjoy most	◯ 4 - With no trouble ◯ 3 - With a little trouble ◯ 2 - With some trouble ◯ 1 - With a lot of trouble ◯ 0 - Not able to do

Anxiety

In the past 7 days I felt like something awful might happen	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I felt nervous	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I felt worried	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I worried when I was at home	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always

Depressive Symptoms

In the past 7 days I felt everything in my life went wrong	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I felt lonely	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always

In the past 7 days I felt sad	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days it was hard for me to have fun	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always

Fatigue

In the past 7 days being tired made it hard for me to keep up with my schoolwork	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I got tired easily	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I was too tired to do sports or other exercise	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I was too tired to enjoy the things I like to do	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always

Peer relationships

In the past 7 days I felt accepted by other kids my age	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days I was able to count on my friends	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days my friends and I helped each other out	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always

In the past 7 days other kids wanted to be my friend	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always

Pain interference

In the past 7 days I had trouble sleeping when I had pain	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days it was hard for me to pay attention when I had pain	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days it was hard for me to run when I had pain	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
In the past 7 days it was hard for me to walk one block when I had pain	◯ 0 - Never ◯ 1 - Almost Never ◯ 2 - Sometimes ◯ 3 - Often ◯ 4 - Almost Always
Pain intensity: In the past 7 days, how bad was your pain on average?	◯ 0 - no pain ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 - worst pain you can think of

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Are you able to do chores such as vacuuming or yard work?	◯ Without any difficulty ◯ With a little difficulty ◯ With some difficulty ◯ With much difficulty ◯ Unable to do
Are you able to go up and down stairs at a normal pace	◯ Without any difficulty ◯ With a little difficulty ◯ With some difficulty ◯ With much difficulty ◯ Unable to do

Are you able to go for a walk of at least 15 minutes?	◯ Without any difficulty ◯ With a little difficulty ◯ With some difficulty ◯ With much difficulty ◯ Unable to do
Are you able to run errands and shop?	◯ Without any difficulty ◯ With a little difficulty ◯ With some difficulty ◯ With much difficulty ◯ Unable to do
In the past 7 days, I felt fearful	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, I found it hard to focus on anything other than my anxiety	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, My worries overwhelmed me	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, I felt uneasy	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, I felt worthless	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, I felt helpless	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, I felt depressed	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, I felt hopeless	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

During the past 7 days, I feel fatigued	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
During the past 7 days, I have trouble starting things because I am tired	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, How run-down did you feel on average?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, How fatigued were you on average?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, My sleep quality was	◯ Very poor ◯ Poor ◯ Fair ◯ Good ◯ Very good
In the past 7 days, My sleep was refreshing	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, I had a problem with my sleep	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, I had difficulty falling asleep	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
I have trouble doing all of my regular leisure activities with others.	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
I have trouble doing all of the family activities that I want to do	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

I have trouble doing all of my usual work (include work at home)	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
I have trouble doing all of the activities with friends that I want to do	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
In the past 7 days, How much did pain interfere with your day to day activities?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, How much did pain interfere with work around the home?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, How much did pain interfere with your ability to participate in social activities?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
In the past 7 days, How much did pain interfere with your household chores?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
How would you rate your pain on average?	◯ No pain ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ Worst imaginable pain

General Well Being (U.S. Health and Nutrition Examination Survey (HANES I)) (PX630701)

The General Well-Being Schedule

(Read: This section of the examination contains questions about how you feel and how things have been going with you. For each question, select the answer which best applies to you.)

1. How have you been feeling in general? (DURING THE PAST MONTH)

- ◯ In excellent spirits
- ◯ In very good spirits
- ◯ In good spirits mostly
- ◯ I have been up and down in spirits a lot
- ◯ In low spirits mostly
- ◯ In very low spirits

2. Have you been bothered by nervousness or your 'nerves'? (DURING THE PAST MONTH)

- ◯ Extremely so - to the point where I could not work or take care of things
- ◯ Very much so
- ◯ Quite a bit
- ◯ Some enough to bother me
- ◯ A little
- ◯ Not at all

3. Have you been in firm control of your behavior, thoughts, emotions, or feelings? (DURING THE PAST MONTH)

- ◯ Yes, definitely so
- ◯ Yes, for the most part
- ◯ Generally so
- ◯ Some - enough to bother me
- ◯ A little
- ◯ Not at all

4. Have you felt so sad, discourages, hopeless, or had so many problems that you wondered if anything was worthwhile? (DURING THE PAST MONTH)

- ◯ Extremely so - to the point that I have just about given up
- ◯ Very much so
- ◯ Quite a bit
- ◯ Some - enough to bother me
- ◯ A little bit
- ◯ Not at all

5. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)

- ◯ Yes, - almost more than I could bear or stand
- ◯ Yes - quite a bit of pressure
- ◯ Yes - some, more than usual
- ◯ Yes - some, but about usual
- ◯ Yes - a little
- ◯ Not at all

6. How happy, satisfied, or pleased have you been with your personal life? (DURING THE PAST MONTH)

- ◯ Extremely happy - could not have been more satisfied or pleased
- ◯ Very happy
- ◯ Fairly happy
- ◯ Satisfied - pleased
- ◯ Somewhat dissatisfied
- ◯ Very dissatisfied

7. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? (DURING THE PAST MONTH)

- ◯ Not at all
- ◯ only a little
- ◯ Some - but not enough to be concerned or worried about
- ◯ Some, and I have been a little concerned
- ◯ Some, and I am quite concerned
- ◯ Yes, very much so, and I am very concerned

8. Have you been anxious, worried, or upset? (DURING THE PAST MONTH)

- ◯ Extremely so
- ◯ Very much so
- ◯ Quite a bit
- ◯ Some - enough to bother me
- ◯ A litle bit
- ◯ Not at all

9. Have you been waking up fresh and rested? (DURING THE PAST MONTH)

- ◯ Every day
- ◯ Most every day
- ◯ Fairly often
- ◯ Less than half the time
- ◯ Rarely
- ◯ None of the time

10. Have you been bothered by any illness, bodily disorder, pains, or fears about your health? (DURING THE PAST MONTH)

- ◯ All the time
- ◯ Most of the time
- ◯ A good bit of the tiem
- ◯ Some of the time
- ◯ A little of the time
- ◯ None of the time

11. Has your daily life been full of things that were interesting to you? (DURING THE PAST MONTH)

- ◯ All the time
- ◯ Most of the time
- ◯ A good bit of the tiem
- ◯ Some of the time
- ◯ A little of the time
- ◯ None of the time

12. Have you felt down hearted and blue? (DURING THE PAST MONTH)

- ◯ All the time
- ◯ Most of the time
- ◯ A good bit of the tiem
- ◯ Some of the time
- ◯ A little of the time
- ◯ None of the time

13. Have you been feeling emotionally stable and sure of yourself? (DURING THE PAST MONTH)

- ◯ All the time
- ◯ Most of the time
- ◯ A good bit of the tiem
- ◯ Some of the time
- ◯ A little of the time
- ◯ None of the time

14. Have you felt tired, worn out, used-up, or exhausted? (DURING THE PAST MONTH)

- ◯ All the time
- ◯ Most of the time
- ◯ A good bit of the tiem
- ◯ Some of the time
- ◯ A little of the time
- ◯ None of the time

For each of the four scales below, note that the words at each end of the 0 to 10 scale describe opposite feelings. Select any number which seems closest to how you have generally felt? (DURING THE PAST MONTH)

15. How concerned or worried about your HEALTH have you been? (DURING THE PAST MONTH)

- ◯ Not concerned at all
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8
- ◯ 9
- ◯ Very concerned

16. How RELAXED or TENSE have you been? (DURING THE PAST MONTH)	◯ Very relaxed ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ Very tense
17. How much ENERGY, PEP, and VITALITY have you felt? (DURING THE PAST MONTH)	◯ No energy AT ALL listless ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ Very ENERGETIC, dynamic
18. How DEPRESSED or CHEERFUL have you been? (DURING THE PAST MONTH)	◯ Very depressed ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ Very cheerful

Scoring:
Items 1, 3, 6, 7, 9, 11, 15, and 16 are reverse scored. The scores from all items are added together and 14 are subtracted from the total to give a range of 0-110. There are three proposed cut-points: total scores of 0-60 reflect "severe distress," 61-72 "moderate distress," and 73-110 "positive well-being".
Six sub-scores can be derived.
Subscore Label \ Question topics
Anxiety:
2. nervousness
5. strain, stress, or pressure
8. anxious, worried, upset
16. relaxed, tense
Depression:
4. sad, discouraged, hopeless
12. down-hearted, blue
18. depressed
Positive well-being:
1. feeling in general
6. happy, satisfied with life
11. interesting daily life
Self-control:
3. firm control of behavior, emotions
7. afraid losing mind, or losing control
13. emotionally stable, sure of self
Vitality:
9. waking fresh, rested
14. feeling tired, worn out
17. energy level
General health:
10. bothered by illness
15. concerned, worried about health

PhenX: Quality of Care - Adults (PhenX protocol PX0820101 unless stated otherwise)

Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me)
Answer all the questions by selecting the best answer to the right of the questions.
? You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

[ ] Yes ? If Yes, Go to Question 1
[ ] No

1. In the past 12 months, did you try to make an appointment to see a doctor or nurse?	◯ Yes ◯ No (If No, Go to Question 4)
2. In the past 12 months, when you tried to make an appointment to see a doctor or nurse, how often were you able to get one as soon as you wanted?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
3. In the past 12 months, how often were you satisfied with the care you received during these scheduled appointments?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
4. Do you have a doctor or nurse who you usually see if you need a check-up, want advice about a health problem, or get sick or hurt?	◯ Yes ◯ No (If No, Go to Question 13)
5. In the past 12 months, how many visits have you had with this doctor or nurse?	◯ 0 visits (If 0 visits, Go to Question 13) ◯ 1 visit ◯ 2 visits ◯ 3 visits ◯ 4 or more visits
6. In the past 12 months, how often did this doctor or nurse explain things in a way that is easy to understand?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
7. In the past 12 months, how often did this doctor or nurse listen carefully to you?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
8. In the past 12 months, how often did this doctor or nurse treat you with courtesy and respect?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
9. In the past 12 months, how often did this doctor or nurse spend enough time with you?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
10. In the past 12 months, how often were you satisfied with the care you received from this doctor or nurse?	◯ Never ◯ Sometimes ◯ Usually ◯ Always

11. How much does this doctor or nurse know how sickle cell affects you personally?	◯ Nothing ◯ A little bit ◯ Some ◯ Quite a bit ◯ Very much
12. Does this doctor or nurse treat a lot of patients with sickle cell disease?	◯ Yes ◯ No
13. In the past 12 months, did you go to an emergency room for any sickle cell care you needed right away?	◯ Yes ◯ No (If No, Go to Question 19)
14. In the past 12 months, when you went to the emergency room for this care, how often did you get it as soon as you wanted?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
15. In the past 12 months, when you went to the emergency room for this care, how often did the DOCTORS treating you seem to really care about you?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
16. In the past 12 months, when you went to the emergency room for this care, how often did the NURSES treating you seem to really care about you?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
17. In the past 12 months, when you went to the emergency room for this care, how often did the clerks and receptionists treat you with courtesy and respect?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
18. In the past 12 months, when you went to the emergency room for this care, how often were you satisfied with the care you received?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
19. In the past 12 months, how many times did you manage a pain attack (crisis) at home without going to a doctor, clinic, or hospital?	◯ I did not have a pain attack (crisis) in the past 12 months (If you did not have a pain attack in the last 12 months, Go to Question 27) ◯ 0 times ◯ 1 time ◯ 2 times ◯ 3 times ◯ 4 or more times
20. In the past 12 months, did you ever delay or avoid going to an emergency room when you thought you needed care?	◯ Yes, I did not always go for care when I needed it ◯ No, I always went for care when I thought I needed it (If No, Go to Question 23)
21. How important were bad experiences in the emergency room in your decision to avoid going for care?	◯ Not at all ◯ A little ◯ Somewhat ◯ Quite ◯ Very

22. How important were health insurance issues in your decision to avoid going for care?

- ◯ Not at all
- ◯ A little
- ◯ Somewhat
- ◯ Quite
- ◯ Very

23. In the past 12 months, how many times did you go to the emergency room because of a pain attack (crisis)?

- ◯ 0 times (If 0 times, Go to Question 27)
- ◯ 1 time
- ◯ 2 times
- ◯ 3 times
- ◯ 4 or more times

24. In the past 12 months, how much were the emergency room doctors and nurses able to help your pain?

- ◯ Not at all
- ◯ A little bit
- ◯ Somewhat
- ◯ Quite a bit
- ◯ Very much

25. In the past 12 months, how much did the emergency room doctors and nurses believe that you had very bad sickle cell pain?

- ◯ Not at all
- ◯ A little bit
- ◯ Somewhat
- ◯ Quite a bit
- ◯ Very much

26. In the past 12 months, what is the longest you had to wait in the emergency room before your sickle cell pain was treated?

- ◯ Less than 5 minutes
- ◯ 5 to 15 minutes
- ◯ 16 minutes to 1 hour
- ◯ More than 1 hour but less than 2 hours
- ◯ 2 hours or more

27. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate all of the care you received for your health in the last 12 months?

- ◯ 0 Worst care possible
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8
- ◯ 9
- ◯ 10 Best care possible

Quality of Care - Children (PhenX protocol PX0820102 unless stated otherwise)

The Consumer Assessment of Healthcare Providers and Systems (CAHPS?) Health Plan Survey 4.0 Child Medicaid Questionnaire
Survey Instructions:
Answer each question by selecting the best answer to the right of the question.
You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:
Yes ? If Yes, go to # 1
Please answer the questions for the child listed. Please do not answer for any other children.

1. Our records show that your child is now in {INSERT HEALTH PLAN NAME}. Is that right?

- ◯ Yes ? If Yes, go to # 3
- ◯ No

2. What is the name of your child's health plan?

_____

Your Child's Health Care in the Last 6 Months:
These questions ask about your child's health care. Do not include care your child got when he or she stayed overnight in a hospital. Do not include the times your child went for dental care visits.

3. In the last 6 months, did your child have an illness, injury, or condition that needed care right away in a clinic, emergency room, or doctor's office?	◯ Yes ◯ No ? If No, go to #5
4. In the last 6 months, when your child needed care right away, how often did your child get care as soon as you thought he or she needed?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
5. In the last 6 months, not counting the times your child needed care right away, did you make any appointments for your child's health care at a doctor's office or clinic?	◯ Yes ◯ No ? If No, go to #7
6. In the last 6 months, not counting the times your child needed care right away, how often did you get an appointment for health care at a doctor's office or clinic as soon as you thought your child needed?	◯ Never ◯ Sometimes ◯ Usually
7. In the last 6 months, not counting the times your child went to an emergency room, how many times did he or she go to a doctor's office or clinic to get health care?	◯ None ? If None, go to #9 [If items CC5-CC7 or CC5-CC18 are included: go to #CC5; if only items CC8-CC18 are included: go to #CC8] ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 to 9 ◯ 10 or more
CC1. In the last 6 months, how often did you have your questions answered by your child's doctors or other health providers?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
CC2. Choices for your child's treatment or health care can include choices about medicine, surgery, or other treatment. In the last 6 months, did your child's doctor or other health provider tell you there was more than one choice for your child's treatment or health care?	◯ Yes ◯ No ? If No, go to #8
CC3. In the last 6 months, did your child's doctor or other health provider talk with you about the pros and cons of each choice for your child's treatment or health care?	◯ Yes ◯ No
CC4. In the last 6 months, when there was more than one choice for your child's treatment or health care, did your child's doctor or other health provider ask you which choice was best for your child?	◯ Yes ◯ No

8. Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all your child's health care in the last 6 months?	◯ 0 Worst health care possible ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 Best health care possible
CC5. Is your child now enrolled in any kind of school or daycare?	◯ Yes ◯ No ? If No, go to #9 [If items CC8-CC18 are included: go to #CC8]
CC6. In the last 6 months, did you need your child's doctors or other health providers to contact a school or daycare center about your child's health or health care?	◯ Yes ◯ No ? If No, go to #9 [If items CC8-CC18 are included: go to #CC8]
CC7. In the last 6 months, did you get the help you needed from your child's doctors or other health providers in contacting your child's school or daycare?	◯ Yes ◯ No
Option: Insert additional questions about general health care here. Specialized Services	
CC8. Special medical equipment or devices include a walker, wheelchair, nebulizer, feeding tubes, or oxygen equipment. In the last 6 months, did you get or try to get any special medical equipment or devices for your child?	◯ Yes ◯ No ? If No, go to #CC11
CC9. In the last 6 months, how often was it easy to get special medical equipment or devices for your child?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
CC10. Did anyone from your child's health plan, doctor's office, or clinic help you get special medical equipment or devices for your child?	◯ Yes ◯ No
CC11. Does your child need or get special therapy such as physical, occupational, or speech therapy?	◯ Yes ◯ No ? If No, go to #CC14
CC12. In the last 6 months, how often was it easy to get this therapy for your child?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
CC13. Did anyone from your child's health plan, doctor's office, or clinic help you get this therapy for your child?	◯ Yes ◯ No

CC14. In the last 6 months, did you get or try to get treatment or counseling for your child for an emotional, developmental, or behavioral problem?	◯ Yes ◯ No ? If No, go to #CC17
CC15. In the last 6 months, how often was it easy to get this treatment or counseling for your child?	◯ Never ◯ Sometimes ◯ Usually
CC16. Did anyone from your child's health plan, doctor's office, or clinic help you get this treatment or counseling for your child?	◯ Yes ◯ No
CC17. In the last 6 months, did your child get care from more than one kind of health care provider or use more than one kind of health care service?	◯ Yes ◯ No
CC18. In the last 6 months, did anyone from your child's health plan, doctor's office, or clinic help coordinate your child's care among these different providers or services?	◯ Yes ◯ No
Your Child's Personal Doctor	
9. A personal doctor is the one your child would see if he or she needs a check-up or gets sick or hurt. Does your child have a personal doctor?	◯ Yes ◯ No ? If No, go to #19
10. In the last 6 months, how many times did your child visit his or her personal doctor for care?	◯ None ? If None, go to #18 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 to 9 ◯ 10 or more
11. In the last 6 months, how often did your child's personal doctor explain things in a way that was easy to understand?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
12. In the last 6 months, how often did your child's personal doctor listen carefully to you?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
13. In the last 6 months, how often did your child's personal doctor show respect for what you had to say?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
14. Is your child able to talk with doctors about his or her health care?	◯ Yes ◯ No ? If No, go to #16
15. In the last 6 months, how often did your child's personal doctor explain things in a way that was easy for your child to understand?	◯ Never ◯ Sometimes ◯ Usually ◯ Always

16. In the last 6 months, how often did your child's personal doctor spend enough time with your child?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
17. In the last 6 months, did your child's personal doctor talk with you about how your child is feeling, growing, or behaving?	◯ Yes ◯ No
18. Using any number from 0 to 10, where 0 is the worst personal doctor possible and 10 is the best personal doctor possible, what number would you use to rate your child's personal doctor?	◯ 0 Worst personal doctor possible ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 Best personal doctor possible
CC19. Does your child have any medical, behavioral, or other health conditions that have lasted for more than 3 months?	◯ Yes ◯ No ? If No, go to #19
CC20. Does your child's personal doctor understand how these medical, behavioral, or other health conditions affect your child's day-to-day life?	◯ Yes ◯ No
CC21. Does your child's personal doctor understand how your child's medical, behavioral, or other health conditions affect your FAMILY'S day-to-day life?	◯ Yes ◯ No
Option: Insert additional questions about personal doctor here. Getting Health Care From a Specialist	
19. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. In the last 6 months, did you try to make any appointments for your child to see a specialist?	◯ Yes ◯ No ? If No, go to #23
20. In the last 6 months, how often was it easy to get appointments for your child with specialists?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
21. How many specialists has your child seen in the last 6 months?	◯ 0 None ? If None, go to #23 ◯ 1 specialist ◯ 2 ◯ 3 ◯ 4 ◯ 5 or more specialists

22. We want to know your rating of the specialist your child saw most often in the last 6 months. Using any number from 0 to 10, where 0 is the worst specialist possible and 10 is the best specialist possible, what number would you use to rate that specialist?	◯ 0 Worst specialist possible ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 Best specialist possible

Option: Insert additional questions about specialist care here.

Your Child's Health Plan

23. In the last 6 months, did you try to get any kind of care, tests, or treatment for your child through his or her health plan?	◯ Yes ◯ No ? If No, go to #25
24. In the last 6 months, how often was it easy to get the care, tests, or treatment you thought your child needed through his or her health plan?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
25. In the last 6 months, did you try to get information or help from customer service at your child's health plan?	◯ Yes ◯ No ? If No, go to #28
26. In the last 6 months, how often did customer service at your child's health plan give you the information or help you needed?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
27. In the last 6 months, how often did customer service staff at your child's health plan treat you with courtesy and respect?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
28. In the last 6 months, did your child's health plan give you any forms to fill out?	◯ Yes ◯ No ? If No, go to #30
29. In the last 6 months, how often were the forms from your child's health plan easy to fill out?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
30. Using any number from 0 to 10, where 0 is the worst health plan possible and 10 is the best health plan possible, what number would you use to rate your child's health plan?	◯ 0 Worst health plan possible ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 Best health plan possible

Option: Insert additional questions about the health plan here.

Prescription Medicines

CC22. In the last 6 months, did you get or refill any prescription medicines for your child?	◯ Yes ◯ No - If NO, go to #31
CC23. In the last 6 months, how often was it easy to get prescription medicines for your child through his or her health plan?	◯ Never ◯ Sometimes ◯ Usually ◯ Always
CC24. Did anyone from your child's health plan, doctor's office, or clinic help you get your child's prescription medicines?	◯ Yes ◯ No
About Your Child and You	
31. In general, how would you rate your child's overall health?	◯ Excellent ◯ Very Good ◯ Good ◯ Fair ◯ Poor
CC25. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?	◯ Yes ◯ No ? If No, go to #CC28
CC26. Is this because of any medical, behavioral, or other health condition?	◯ Yes ◯ No ? If No, go to #CC28
CC27. Is this a condition that has lasted or is expected to last for at least 12 months?	◯ Yes ◯ No
CC28. Does your child need or use more medical care, more mental health services, or more educational services than is usual for most children of the same age?	◯ Yes ◯ No - If NO, go to #CC31
CC29. Is this because of any medical, behavioral, or other health condition?	◯ Yes ◯ No ? If No, go to #CC31
CC30. Is this a condition that has lasted or is expected to last for at least 12 months?	◯ Yes ◯ No
CC31. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?	◯ Yes ◯ No ? If No, go to #CC34
CC32. Is this because of any medical, behavioral, or other health condition?	◯ Yes ◯ No ? If No, go to #CC34
CC33. Is this a condition that has lasted or is expected to last for at least 12 months?	◯ Yes ◯ No
CC34. Does your child need or get special therapy such as physical, occupational, or speech therapy?	◯ Yes ◯ No ? If No, go to #CC37
CC35. Is this because of any medical, behavioral, or other health condition?	◯ Yes ◯ No ? If No, go to #CC37

CC36. Is this a condition that has lasted or is expected to last for at least 12 months?	◯ Yes ◯ No
CC37. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?	◯ Yes ◯ No ? If No, go to #32
CC38. Has this problem lasted or is it expected to last for at least 12 months?	◯ Yes ◯ No
32. What is your child's age?	◯ Less than 1 year old ◯ _____ YEARS OLD (write in below)
32a. What is your child's age? Write in	_____
33. Is your child male or female?	◯ Male ◯ Female
34. Is your child of Hispanic or Latino origin or descent?	◯ Yes, Hispanic or Latino ◯ No, not Hispanic or Latino
35. What is your child's race? Please mark one or more.	☐ White ☐ Black or African-American ☐ Asian ☐ Native Hawiian or other Pacific Islander ☐ American Indian or Alsaka Native ☐ Other
36. What is your age?	◯ Under 18 ◯ 18 to 24 ◯ 25 to 34 ◯ 35 to 44 ◯ 45 to 54 ◯ 55 to 64 ◯ 65 to 74 ◯ 75 or older
37. Are you male or female?	◯ Male ◯ Female
38. What is the highest grade or level of school that you have completed?	◯ 8th grade or less ◯ Some high school, but did not graduate ◯ High school graduate or GED ◯ Some college or 2-year degree ◯ 4-year college graduate ◯ More than 4-year college degree
39. How are you related to the child?	◯ Mother or father ◯ Grandparent ◯ Aunt or uncle ◯ Older sibling ◯ Other relative ◯ Legal guardian
40. Did someone help you complete this survey?	◯ Yes ◯ No ? Thank you.

Adolescent/ Pediatric pain tool appt (PhenX protocol PX190902 unless stated otherwise)

Code	_____
Date	_____
Color in the areas on these drawings to show where you have pain. Make the marks as big or small as the place where the pain is.	_____
Place a straight, up and down mark on this line to show how much pain you have.	◯ No Pain ◯ Little Pain ◯ Medium Pain ◯ Large Pain ◯ Worst Possible Pain
Point to or circle as many of these words that describe your pain	◯ annoying, bad, horrible, miserable, terrible, uncomfortable ◯ aching, hurting, like an ache, like a hurt, sore ◯ beating, hitting, pounding, punching, throbbing ◯ biting, cutting, like a pin, like a sharp knife, pin like, sharp, stabbing ◯ blistering, burning, hot ◯ cramping, crushing, like a pinch, pinching, pressure ◯ itching, like a scratch, like a sting, scratching, stinging ◯ shocking, shooting, splitting ◯ numb, stiff, swollen, tight ◯ awful, deadly, dying, killing ◯ crying, frightening, screaming, terrifying ◯ dizzy, sickening, suffocating ◯ never goes away, uncontrollable ◯ always, comes and goes, comes on all of a sudden, constant, continuous, forever ◯ off and on, once in a while, sneaks up, sometimes, steady ◯ If you like, you may add other words: _____ _____ _____
Point to or circle as many of these words that describe your pain: If you like, you may add other words	_____
Point to or circle as many of these words that describe your pain: If you like, you may add other words	_____
Point to or circle as many of these words that describe your pain: If you like, you may add other words	_____

Adult sickle cell quality of life - Measurement Information (PhenX protocol PX0820201 unless stated otherwise)

Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me)
Answer all the questions by checking the box to the left of your answer.
Emotional Impact

1. In the past 7 days, how often did you feel completely hopeless because of your health?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
2. In the past 7 days, how lonely did you feel because of your health problems?	◯ Not at all ◯ A little ◯ Somewhat ◯ Quite ◯ Very
3. In the past 7 days, how depressed were you about your health problems?	◯ Not at all ◯ A little ◯ Somewhat ◯ Quite ◯ Very
4. In the past 7 days, how much did you worry about getting sick?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
5. In the past 7 days, how often were you very worried about needing to go to the hospital?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

Social Functioning Impact

1. In the past 30 days, how much did you rely on others to take care of you because of your health?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much
2. In the past 30 days, how often did your health slow you down?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
3. In the past 30 days, how often did your health make it hard for you to do things?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

4. In the past 30 days, how often did your health keep you from going out?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
5. In the past 30 days, how much did your health make it hard for you to do things with your friends?	◯ Not at all ◯ A little bit ◯ Somewhat ◯ Quite a bit ◯ Very much

Sleep Impact

1. In the past 7 days, how often did you stay up most of the night because you could not fall asleep?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
2. In the past 7 days, how often was it very easy for you to fall asleep?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
3. In the past 7 days, how often did you have a lot of trouble falling asleep?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
4. In the past 7 days, how often did you stay up all night because you could not fall asleep?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
5. In the past 7 days, how often did you stay up half of the night because you could not fall asleep?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

Stiffness Impact

1. In the past 7 days, how often were your joints very stiff when you woke up?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
2. In the past 7 days, how often were your joints very stiff during the day?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

3. In the past 7 days, how often were your joints so stiff during the day that you could not move?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
4. In the past 7 days, how often did you wake up so stiff that you could not move?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
5. In the past 7 days, how often did it take you a very long time to get out of bed because of stiffness?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

Pain Impact

1. In the past 7 days, how often did you have pain so bad that you could not do anything for a whole day?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
2. In the past 7 days, how often did you have pain so bad that you could not get out of bed?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
3. In the past 7 days, how often did you have very severe pain?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
4. In the past 7 days, how often did you have pain so bad that you had to stop what you were doing?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always
5. In the past 7 days, how often did you have pain so bad that it was hard to finish what you were doing?	◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

Pain Episodes

1. In the past 12 months, how many sickle cell pain attacks (crises) did you have?	◯ I did not have a pain attack (crises) in the past 12 months ◯ 1 ◯ 2 ◯ 3 ◯ 4 or more

2. When was your last pain attack (crisis)?

- ◯ I've never had a pain attack (crisis)
- ◯ More than 5 years ago
- ◯ 1-5 years ago
- ◯ 7-11 months ago
- ◯ 1-6 months ago
- ◯ 1-3 weeks ago
- ◯ Less than a week ago
- ◯ I have one right now

3. Using any number from 0 to 10, where 0 is no pain and 10 is the worst pain imaginable, how severe was your pain during your last pain attack (crisis)?

- ◯ No pain
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8
- ◯ 9
- ◯ Worst pain imaginable
- ◯ I've never had a pain attack (crisis)

4. How much did your last pain attack (crisis) interfere with your life?

- ◯ I've never had a pain attack (crisis)
- ◯ Not at all, I did everything I usually do
- ◯ I had to cut down on some things I usually do
- ◯ I could not do most things I usually do
- ◯ I could not take care of myself and needed some help from family or friends
- ◯ I could not take care of myself and needed constant care from family, friends, doctors, or nurses

5. About how long did your most recent pain attack (crisis) last?

- ◯ I've never had a pain attack (crisis)
- ◯ Less than 1 hour
- ◯ 1-12 hours
- ◯ 13-23 hours
- ◯ 1-3 days
- ◯ 4-6 days
- ◯ 1-2 weeks
- ◯ More than 2 weeks

Scoring information is available from
Keller S. D., Evensen, C., Yang, M., & Owens, T. (2011). Adult Sickle Cell Quality of Life Measurement Information System user's manual and interpretation guide. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung and Blood Institute.

Self-efficacy in sickle cell disease (PhenX protocol PX0820401 unless stated otherwise)

Sickle Cell Disease Self-Efficacy Scale
The following questions ask about how sure you are in dealing day-to-day with sickle cell disease. There are no right or wrong answers; we just want to know what you think. So for each question, tell us how sure you are by checking the response that best tells how you feel. Please answer every question.

1. How sure are you that you can do something to cut down on most of the pain?

- ◯ Not Sure at All
- ◯ Not Sure
- ◯ Neither
- ◯ Sure
- ◯ Very Sure

2. How sure are you that you can keep doing most of the things you do day-to-day?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure
3. How sure are you that you can keep sickle cell disease pain from interfering with your sleep?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure
4. How sure are you that you can reduce your sickle cell disease pain by using methods other than taking medications?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure
5. How sure are you that you can control how often or when you get tired?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure
6. How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure
7. As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure
8. How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure
9. How sure are you that you can deal with the frustration of having sickle cell disease?	◯ Not Sure at All ◯ Not Sure ◯ Neither ◯ Sure ◯ Very Sure

Scoring:
Responses from individual items are summed to give an overall score, with higher scores indicating greater self-efficacy.

Stroke impact scale - SIS adults (PhenX protocol P0820701 unless stated otherwise)

Stroke Impact Scale
VERSION 3.0
The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from YOUR POINT OF VIEW how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke.

These questions are about the physical problems which may have occurred as a result of your stroke.

1a. In the past week, how would you rate the strength of your arm that was most affected by your stroke?

- ◯ A lot of strength
- ◯ Quite a bit of strength
- ◯ Some strength
- ◯ A little strength
- ◯ No strength at all

1b. In the past week, how would you rate the strength of your grip of your hand that was most affected by your stroke?

- ◯ A lot of strength
- ◯ Quite a bit of strength
- ◯ Some strength
- ◯ A little strength
- ◯ No strength at all

1c. In the past week, how would you rate the strength of your leg that was most affected by your stroke?

- ◯ A lot of strength
- ◯ Quite a bit of strength
- ◯ Some strength
- ◯ A little strength
- ◯ No strength at all

1d. In the past week, how would you rate the strength of your foot/ankle that was most affected by your stroke?

- ◯ A lot of strength
- ◯ Quite a bit of strength
- ◯ Some strength
- ◯ A little strength
- ◯ No strength at all

These questions are about your memory and thinking.

2a. In the past week, how difficult was it for you to remember things that people just told you?

- ◯ Not difficult at all
- ◯ A little difficult
- ◯ Somewhat difficult
- ◯ Very difficult
- ◯ Extremely difficult

2b. In the past week, how difficult was it for you to remember things that happened the day before?

- ◯ Not difficult at all
- ◯ A little difficult
- ◯ Somewhat difficult
- ◯ Very difficult
- ◯ Extremely difficult

2c. In the past week, how difficult was it for you to remember to do things (e.g., keep scheduled appointments or take medication)?

- ◯ Not difficult at all
- ◯ A little difficult
- ◯ Somewhat difficult
- ◯ Very difficult
- ◯ Extremely difficult

2d. In the past week, how difficult was it for you to remember the day of the week?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
2e. In the past week, how difficult was it for you to concentrate?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
2f. In the past week, how difficult was it for you to think quickly?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
2g. In the past week, how difficult was it for you to solve everyday problems?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke

3a. In the past week, how often did you feel sad?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
3b. In the past week, how often did you feel that there is nobody you are close to?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
3c. In the past week, how often did you feel that you are a burden to others?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
3d. In the past week, how often did you feel that you have nothing to look forward to?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
3e. In the past week, how often did you blame yourself for mistakes that you made?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time

3f. In the past week, how often did you enjoy things as much as ever?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
3g. In the past week, how often did you feel quite nervous?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
3h. In the past week, how often did you feel that life is worth living?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
3i. In the past week, how often did you smile and laugh at least once a day?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.

4a. In the past week, how difficult was it to say the name of someone who was in front of you?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
4b. In the past week, how difficult was it to understand what was being said to you in a conversation?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
4c. In the past week, how difficult was it to reply to questions?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
4d. In the past week, how difficult was it to correctly name objects?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
4e. In the past week, how difficult was it to participate in a conversation with a group of people?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult

4f. In the past week, how difficult was it to have a conversation on the telephone?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult
4g. In the past week, how difficult was it to call another person on the telephone, including selecting the correct phone number and dialing?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Extremely difficult

The following questions ask about activities you might do during a typical day.

5a. In the past 2 weeks, how difficult was it to cut your food with a knife and fork?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5b. In the past 2 weeks, how difficult was it to dress the top part of your body?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5c. In the past 2 weeks, how difficult was it to bathe yourself?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5d. In the past 2 weeks, how difficult was it to clip your toenails?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5e. In the past 2 weeks, how difficult was it to get to the toilet on time?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5f. In the past 2 weeks, how difficult was it to control your bladder (not have an accident)?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5g. In the past 2 weeks, how difficult was it to control your bowels (not have an accident)?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all

5h. In the past 2 weeks, how difficult was it to do light household tasks/chores (e.g., dust, make a bed, take out garbage, do the dishes)?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5i. In the past 2 weeks, how difficult was it to go shopping?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
5j. In the past 2 weeks, how difficult was it to do heavy household chores (e.g., vacuum, laundry or yard work)?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all

The following questions are about your ability to be mobile at home and in the community.

6a. In the past 2 weeks, how difficult was it to stay sitting without losing your balance?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
6b. In the past 2 weeks, how difficult was it to stay standing without losing your balance?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
6c. In the past 2 weeks, how difficult was it to walk without losing your balance?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
6d. In the past 2 weeks, how difficult was it to move from a bed to a chair?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
6e. In the past 2 weeks, how difficult was it to walk one block?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
6f. In the past 2 weeks, how difficult was it to walk fast?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all

6g. In the past 2 weeks, how difficult was it to climb one flight of stairs?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
6h. In the past 2 weeks, how difficult was it to climb several flights of stairs?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
6i. In the past 2 weeks, how difficult was it to get in and out of a car?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

7a. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to carry heavy objects (e.g., bag of groceries)?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
7b. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to turn a doorknob?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
7c. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to open a can or jar?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
7d. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to tie a shoe lace?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all
7e. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to pick up a dime?	◯ Not difficult at all ◯ A little difficult ◯ Somewhat difficult ◯ Very difficult ◯ Could not do at all

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

8a. During the past 4 weeks, how much of the time have you been limited in your work (paid, voluntary or other)?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time

8b. During the past 4 weeks, how much of the time have you been limited in your social activities?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
8c. During the past 4 weeks, how much of the time have you been limited in quiet recreation (crafts, reading)?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
8d. During the past 4 weeks, how much of the time have you been limited in active recreation (sports, outings, travel)?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
8e. During the past 4 weeks, how much of the time have you been limited in your role as a family member and/or friend?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
8f. During the past 4 weeks, how much of the time have you been limited in your participation in spiritual or religious activities?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
8g. During the past 4 weeks, how much of the time have you been limited in your ability to control your life as you wish?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
8h. During the past 4 weeks, how much of the time have you been limited in your ability to help others?	◯ None of the time ◯ A little of the time ◯ Some of the time ◯ Most of the time ◯ All of the time
Stroke Recovery	
9. On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?	◯ Full Recovery ◯ 90 ◯ 80 ◯ 70 ◯ 60 ◯ 50 ◯ 40 ◯ 30 ◯ 20 ◯ 10 ◯ No Recovery

Scoring: Each item is rated in a 5-point Likert scale in terms of the difficulty the patient has experienced in completing each item. A score of 1 = an inability to complete the item and a score of 5 = no difficulty experienced at all. Summative scores are generated for each domain. Domain scores range from 0-100.
The Stroke Impact Scale (SIS) is scored in the following way, for each domain:
Transformed Scale = [(Actual raw score - lowest possible raw score) / Possible raw score range] x 100
Three items in the emotion domain, 3f, 3h, and 3i, are reverse-scored, i.e., 1 becomes 5, 2 becomes 4, 3 remains the same, 4 becomes 2, and 5 becomes 1, prior to manual calculation. For these items, use the following equation to compute the individual's score:
6 - individual's rating = item score
The last item assesses the participant's overall perception of recovery and is presented in the form of a visual analog scale from 0 to 100, where 0 = "no recovery" and 100 = "full recovery."

Recovery and recurrence questionaire - RRQ pediatrics (PhenX protocol PX0820702 unless stated otherwise)

International Pediatric Stroke Study (IPSS) Recovery and Recurrence Questionnaire
Note: If child has died since discharge from hospital, please go directly to item 8 (skip items 1-7)

1. Has your child recovered completely from the stroke?	◯ Yes ◯ No - If no, please answer the following questions:
1A. Does your child have any problems with strength, coordination, or sensation including vision or hearing, as a result of the stroke? If yes, please choose which of the following are present in your child:	☐ Developmental delay ☐ Abnormal tone ☐ Weakness on one side of the body ☐ Weakness on one side of the face ☐ Unsteadiness on one side of the body ☐ Difficulty with hearing ☐ Difficulty with speaking clearly (problem with pronouncing words) ☐ Difficulty with drinking, chewing, or swallowing ☐ Loss of sensation on one side of the body ☐ Other sensory problems ☐ Difficulty with vision ☐ Other problems with strength or coordination; Describe below in Q 1Aa
1Aa. Does your child have any problems with strength, coordination, or sensation including vision or hearing, as a result of the stroke? Please describe	_____
1a1. Does the problem affect your child's day-to-day activities?	◯ Yes ◯ No
Left side face or body	◯ Not Done ◯ None ◯ Mild but no impact on function ◯ Moderate with some limitations with daily functions ◯ Severe or Profound with missing function
Right side face or body	◯ Not Done ◯ None ◯ Mild but no impact on function ◯ Moderate with some limitations with daily functions ◯ Severe or Profound with missing function

1B. Does your child have difficulty expressing him/herself verbally? (Exclude dysarthrias or pronunciation problems)	◯ Not Done ◯ None ◯ Mild but no impact on function ◯ Moderate with some limitations with daily functions ◯ Severe or Profound with missing function
1B1. Does your child have difficulty expressing him/herself verbally? (Exclude dysarthrias or pronunciation problems)	_____
1C. Does your child have difficulty understanding what is said to her/him?	◯ Not Done ◯ None ◯ Mild but no impact on function ◯ Moderate with some limitations with daily functions ◯ Severe or Profound with missing function
1C1. Does your child have difficulty understanding what is said to her/him? Please describe	_____
1D. Does your child have difficulty with his/her thinking or behavior?	◯ Not Done ◯ None ◯ Mild but no impact on function ◯ Moderate with some limitations with daily functions ◯ Severe or Profound with missing function
1D1. Does your child have difficulty with his/her thinking or behavior? Please describe	_____
2. Does your child need extra help with day-to-day activities compared with other children of the same age?	◯ Yes ◯ No
3. Since the first stroke, has your child had another Stroke or Transient Ischemic Attack (TIA) or blood clot in any other blood vessel (e.g. in the leg, lung, heart, other location) ?	◯ Yes ◯ No ◯ Unknown
3a. If yes, which type?	◯ Unknown ◯ Stroke in a brain artery (usual form of ?stroke?) ◯ Stroke in a brain vein (?sinus thrombosis?) ◯ TIA ◯ Other blood clot: describe below
3a1. If yes, which type? Other blood clot: (State location of blood clot :_____)	_____
3b. If yes, when was the recurrence (if unknown, please estimate)? (month/day/year)	_____
3c. Did your child have a CT / MRI at the time of the recurrence?	◯ Yes ◯ No ◯ Unknown
3c1. If yes, which test was done?	◯ CT ◯ MRI ◯ Unknown

3d. If yes, did the CT /MRI show a new stroke?	◯ Yes ◯ No ◯ Unknown
3d1. Describe the new clinical symptoms at the time of the recurrence	☐ Difficulty walking ☐ Difficulty speaking ☐ Difficulty with drinking, chewing or swallowing ☐ Difficulty using hands ☐ Difficulty with vision ☐ Other; please describe below
3d2. Describe the new clinical symptoms at the time of the recurrence: Other, describe	_____
3e. Describe how long the symptoms lasted with the most recent attack	◯ Less than 6hrs ◯ 6-24 hours ◯ More than 24 hours
3e1. If there was more than one episode, how many episodes occurred?_____	_____
3f. What stroke treatment was he/she on at the beginning of the episode?	◯ None ◯ Aspirin ◯ Low molecular weight Heparin (Enoxaparin, Loxaprin, injections under the skin) ◯ Coumadin (blood thinning pill) ◯ Other; please describe below
3f1. What stroke treatment was he/she on at the beginning of the episode? Other (describe)	_____
4. Does your child suffer from headaches since being discharged after the stroke(s)?	◯ Yes ◯ No
4A. Does your child suffer from seizures since being discharged after the stroke(s)?	◯ Yes ◯ No
4B. If yes, is he/she on a seizure medicine now?	◯ Yes ◯ No
5. Have there been any other major health problems or procedures resulting from the stroke(s) or the stroke(s) treatment?	◯ Yes; describe below ◯ No
5A. If yes, please describe:	_____
6. What medications are being used right now for stroke treatment?	◯ None ◯ Aspirin ◯ LMWH (blood thinner injected under the skin) ◯ Coumadin (blood thinner pill) ◯ Other; describe below
6A. What medications are being used right now for stroke treatment? Please describe	_____

7. What rehabilitation treatments is your child receiving now?	◯ None ◯ Occupational Therapy ◯ Physical Therapy ◯ Speech therapy ◯ Special education services ◯ Other; describe below
7A. What rehabilitation treatments is your child receiving now? Please describe	_____
8. If your child is deceased, please specify: Date of death: (month/day/year)	_____
8A. If your child is deceased, please specify: Cause of death:	_____

NIH stroke scale - NIHSS (PhenX protocol PX0820801 unless stated otherwise)

Interval	◯ Baseline ◯ 2 hours post treatment ◯ 24 hours post onset of symptoms ? 20 minutes ◯ 7 - 10 days ◯ 3 months
Interval	_____
Time hour	_____
Time am pm	◯ am ◯ pm
Person Administering Scale	_____

Administer stroke scale items in the order listed. Record performance in each category after each subscale exam. Do not go back and change scores. Follow directions provided for each exam technique. Scores should reflect what the patient does, not what the clinician thinks the patient can do. The clinician should record answers while administering the exam and work quickly. Except where indicated, the patient should not be coached (i.e., repeated requests to patient to make a special effort).

1a. Level of Consciousness: The investigator must choose a response if a full evaluation is prevented by such obstacles as an endotracheal tube, language barrier, orotracheal trauma/bandages. A 3 is scored only if the patient makes no movement (other than reflexive posturing) in response to noxious stimulation.	◯ Alert; keenly responsive. ◯ Not alert; but arousable by minor stimulation to obey, answer, or respond. ◯ Not alert; requires repeated stimulation to attend, or is obtunded and requires strong or painful stimulation to make movements (not stereotyped). ◯ Responds only with reflex motor or autonomic effects or totally unresponsive, flaccid, and areflexic.

1b. LOC Questions: The patient is asked the month and his/her age. The answer must be correct - there is no partial credit for being close. Aphasic and stuporous patients who do not comprehend the questions will score 2. Patients unable to speak because of endotracheal intubation, orotracheal trauma, severe dysarthria from any cause, language barrier, or any other problem not secondary to aphasia are given a 1. It is important that only the initial answer be graded and that the examiner not help" the patient with verbal or non-verbal cues."	◯ Answers both questions correctly. ◯ Answers one question correctly. ◯ Answers neither question correctly.
1c. LOC Commands: The patient is asked to open and close the eyes and then to grip and release the non-paretic hand. Substitute another one step command if the hands cannot be used. Credit is given if an unequivocal attempt is made but not completed due to weakness. If the patient does not respond to command, the task should be demonstrated to him or her (pantomime), and the result scored (i.e., follows none, one or two commands). Patients with trauma, amputation, or other physical impediments should be given suitable one-step commands. Only the first attempt is scored.	◯ Performs both tasks correctly. ◯ Performs one task correctly. ◯ Performs neither task correctly.
2. Best Gaze: Only horizontal eye movements will be tested. Voluntary or reflexive (oculocephalic) eye movements will be scored, but caloric testing is not done. If the patient has a conjugate deviation of the eyes that can be overcome by voluntary or reflexive activity, the score will be 1. If a patient has an isolated peripheral nerve paresis (CN III, IV or VI), score a 1. Gaze is testable in all aphasic patients. Patients with ocular trauma, bandages, pre-existing blindness, or other disorder of visual acuity or fields should be tested with reflexive movements, and a choice made by the investigator. Establishing eye contact and then moving about the patient from side to side will occasionally clarify the presence of a partial gaze palsy.	◯ Normal. ◯ Partial gaze palsy; gaze is abnormal in one or both eyes, but forced deviation or total gaze paresis is not present. ◯ Forced deviation, or total gaze paresis not overcome by the oculocephalic maneuver.
3. Visual: Visual fields (upper and lower quadrants) are tested by confrontation, using finger counting or visual threat, as appropriate. Patients may be encouraged, but if they look at the side of the moving fingers appropriately, this can be scored as normal. If there is unilateral blindness or enucleation, visual fields in the remaining eye are scored. Score 1 only if a clear-cut asymmetry, including quadrantanopia, is found. If patient is blind from any cause, score 3. Double simultaneous stimulation is performed at this point. If there is extinction, patient receives a 1, and the results are used to respond to item 11.	◯ No visual loss. ◯ Partial hemianopia. ◯ Complete hemianopia. ◯ Bilateral hemianopia (blind including cortical blindness).

4. Facial Palsy: Ask - or use pantomime to encourage - the patient to show teeth or raise eyebrows and close eyes. Score symmetry of grimace in response to noxious stimuli in the poorly responsive or non-comprehending patient. If facial trauma/bandages, orotracheal tube, tape or other physical barriers obscure the face, these should be removed to the extent possible.	◯ Normal symmetrical movements. ◯ Minor paralysis (flattened nasolabial fold, asymmetry on smiling). ◯ Partial paralysis (total or near-total paralysis of lower face). ◯ Complete paralysis of one or both sides (absence of facial movement in the upper and lower face).
5. Motor Arm: LEFT ARM - The limb is placed in the appropriate position; extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine). Drift is scored if the arm falls before 10 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder, the examiner should record the score as untestable (UN) and clearly write the explanation for this choice below.	◯ No drift; limb holds 90 (or 45) degrees for full 10 seconds. ◯ Drift; limb holds 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support. ◯ Some effort against gravity; limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity. ◯ No effort against gravity; limb falls. ◯ No movement. ◯ UN , Amputation or joint fusion, explain below:
5a. Motor Arm: LEFT ARM - Only in the case of amputation or joint fusion at the shoulder, the examiner should record the score as untestable (UN) and clearly write the explanation for this choice. Explain:	_____
5b. Motor Arm: RIGHT ARM - The limb is placed in the appropriate position; extend the arms (palms down) 90 degrees (if sitting) or 45 degrees (if supine). Drift is scored if the arm falls before 10 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic arm. Only in the case of amputation or joint fusion at the shoulder, the examiner should record the score as untestable (UN) and clearly write the explanation for this choice.	◯ No drift; limb holds 90 (or 45) degrees for full 10 seconds. ◯ Drift; limb holds 90 (or 45) degrees, but drifts down before full 10 seconds; does not hit bed or other support. ◯ Some effort against gravity; limb cannot get to or maintain (if cued) 90 (or 45) degrees, drifts down to bed, but has some effort against gravity. ◯ No effort against gravity; limb falls. ◯ No movement. ◯ UN, Amputation or joint fusion, explain below:
5c. Motor Arm: RIGHT ARM - Only in the case of amputation or joint fusion at the shoulder, the examiner should record the score as untestable (UN) and clearly write the explanation for this choice. Explain:	_____
6a. Motor Leg: LEFT LEG - The limb is placed in the appropriate position: hold the leg at 30 degrees (always tested supine). Drift is scored if the leg falls before 5 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic leg. Only in the case of amputation or joint fusion at the hip, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice. LEFT LEG	◯ No drift; leg holds 30-degree position for full 5 seconds. ◯ Drift; leg falls by the end of the 5-second period but does not hit bed. ◯ Some effort against gravity; leg falls to bed by 5 seconds, but has some effort against gravity. ◯ No effort against gravity; leg falls to bed immediately. ◯ No movement. ◯ UN , Amputation or joint fusion, explain below:

6b. Motor Leg: LEFT LEG - The limb is placed in the appropriate position: hold the leg at 30 degrees (always tested supine). Drift is scored if the leg falls before 5 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic leg. Only in the case of amputation or joint fusion at the hip, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.

_____

6c. Motor Leg: RIGHT LEG - The limb is placed in the appropriate position: hold the leg at 30 degrees (always tested supine). Drift is scored if the leg falls before 5 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic leg. Only in the case of amputation or joint fusion at the hip, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice.

- ◯ No drift; leg holds 30-degree position for full 5 seconds.
- ◯ Drift; leg falls by the end of the 5-second period but does not hit bed.
- ◯ Some effort against gravity; leg falls to bed by 5 seconds, but has some effort against gravity.
- ◯ No effort against gravity; leg falls to bed immediately.
- ◯ No movement.
- ◯ UN , Amputation or joint fusion, explain below:

6d. Motor Leg: RIGHT LEG - The limb is placed in the appropriate position: hold the leg at 30 degrees (always tested supine). Drift is scored if the leg falls before 5 seconds. The aphasic patient is encouraged using urgency in the voice and pantomime, but not noxious stimulation. Each limb is tested in turn, beginning with the non-paretic leg. Only in the case of amputation or joint fusion at the hip, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice. Explain:

_____

7. Limb Ataxia: This item is aimed at finding evidence of a unilateral cerebellar lesion. Test with eyes open. In case of visual defect, ensure testing is done in intact visual field. The finger-nose-finger and heel-shin tests are performed on both sides, and ataxia is scored only if present out of proportion to weakness. Ataxia is absent in the patient who cannot understand or is paralyzed. Only in the case of amputation or joint fusion, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice. In case of blindness, test by having the patient touch nose from extended arm position.

- ◯ Absent.
- ◯ Present in one limb.
- ◯ Present in two limbs.
- ◯ UN, Amputation or joint fusion, explain below:

7a. Limb Ataxia: Only in the case of amputation or joint fusion, the examiner should record the score as untestable (UN), and clearly write the explanation for this choice. In case of blindness, test by having the patient touch nose from extended arm position. Explain:

_____

8. Sensory: Sensation or grimace to pinprick when tested, or withdrawal from noxious stimulus in the obtunded or aphasic patient. Only sensory loss attributed to stroke is scored as abnormal and the examiner should test as many body areas (arms [not hands], legs, trunk, face) as needed to accurately check for hemisensory loss. A score of 2, 'severe or total sensory loss', should only be given when a severe or total loss of sensation can be clearly demonstrated. Stuporous and aphasic patients will, therefore, probably score 1 or 0. The patient with brainstem stroke who has bilateral loss of sensation is scored 2. If the patient does not respond and is quadriplegic, score 2. Patients in a coma (item 1a=3) are automatically given a 2 on this item.

- ◯ Normal; no sensory loss.
- ◯ Mild-to-moderate sensory loss; patient feels pinprick is less sharp or is dull on the affected side; or there is a loss of superficial pain with pinprick, but patient is aware of being touched.
- ◯ Severe to total sensory loss; patient is not aware of being touched in the face, arm, and leg.

9. Best Language: A great deal of information about comprehension will be obtained during the preceding sections of the examination. For this scale item, the patient is asked to describe what is happening in the attached picture, to name the items on the attached naming sheet and to read from the attached list of sentences. Comprehension is judged from responses here, as well as to all of the commands in the preceding general neurological exam. If visual loss interferes with the tests, ask the patient to identify objects placed in the hand, repeat, and produce speech. The intubated patient should be asked to write. The patient in a coma (item 1a=3) will automatically score 3 on this item. The examiner must choose a score for the patient with stupor or limited cooperation, but a score of 3 should be used only if the patient is mute and follows no one-step commands.

- ◯ No aphasia; normal.
- ◯ Mild-to-moderate aphasia; some obvious loss of fluency or facility of comprehension, without significant limitation on ideas expressed or form of expression.Reduction of speech and/or comprehension, however, makes conversation about provided materials difficult or impossible. For example, in conversation about provided materials, examiner can identify picture or naming card content from patient?s response.
- ◯ Severe aphasia; all communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener. Range of information that can be exchanged is limited; listener carries burden of communication. Examiner cannot identify materials provided from patient response.
- ◯ Mute, global aphasia; no usable speech or auditory comprehension.

IMAGE

10. Dysarthria: If patient is thought to be normal, an adequate sample of speech must be obtained by asking patient to read or repeat words from the attached list. If the patient has severe aphasia, the clarity of articulation of spontaneous speech can be rated. Only if the patient is intubated or has other physical barriers to producing speech, the examiner should record the score as untestable (UN), and clearly write an explanation for this choice. Do not tell the patient why he or she is being tested.

- ◯ Normal.
- ◯ Mild-to-moderate dysarthria; patient slurs at least some words and, at worst, can be understood with some difficulty.
- ◯ Severe dysarthria; patient's speech is so slurred as to be unintelligible in the absence of or out of proportion to any dysphasia, or is mute/anarthric.
- ◯ UN, Intubated or other physical barrier, explain below

10a. Dysarthria: Only if the patient is intubated or has other physical barriers to producing speech, the examiner should record the score as untestable (UN), and clearly write an explanation for this choice. Do not tell the patient why he or she is being tested. Explain:

_____

11. Extinction and Inattention (formerly Neglect): Sufficient information to identify neglect may be obtained during the prior testing. If the patient has a severe visual loss preventing visual double simultaneous stimulation, and the cutaneous stimuli are normal, the score is normal. If the patient has aphasia but does appear to attend to both sides, the score is normal. The presence of visual spatial neglect or anosagnosia may also be taken as evidence of abnormality. Since the abnormality is scored only if present, the item is never untestable.

- ◯ No abnormality.
- ◯ Visual, tactile, auditory, spatial, or personal inattention or extinction to bilateral simultaneous stimulation in one of the sensory modalities.
- ◯ Profound hemi-inattention or extinction to more than one modality; does not recognize own hand or orients to only one side of space.

IMAGE

IMAGE

IMAGE

Trans Cranial Doppler Ultrasonography (TCD) (PhenX protocol PX0821001 unless stated otherwise)

Transcranial Doppler Ultrasonography
Identifying Intracranial Landmarks and Major Cerebral Arteries
Transcranial Doppler (TCD) ultrasonography provides visual landmarks to help correctly identify intracranial blood vessels. Correct identification of intracranial vessels relies on the diameter of the head, position of the transducer, angle of the transducer, depth of the Doppler sample, and direction of the blood flow. In adults, the diameter of the head is assumed to be 130-140 mm, whereas the head diameter must be measured due to variation of children's head sizes. In children, the bitemporal diameter is measured so that the location of the midline can be calculated (half of the diameter of the head). The internal carotid artery (ICA) bifurcation is the landmark that is the reference point for all other intracranial anatomy. The depth of the ICA bifurcation is estimated to usually be 10 to12 millimeters shallower than the midline.
Recording Transcranial Doppler Ultrasonography Results
The results of the TCD are spectral waveform plots of velocity vs. time and the calculated velocity is the time averaged mean of the maximum velocity. Examiners should record the highest time-averaged mean blood-flow velocity in 2-millimeter increments in the following arteries:
*middle cerebral artery (at three points),
*distal internal carotid artery,
*anterior and posterior cerebral arteries, and
*basilar artery.

Highest time-averaged mean blood-flow velocity in the anterior cerebral artery

_____
(millimeters)

Highest time-averaged mean blood-flow velocity in the basilar artery

_____
(millimeters)

Child bitemporal diameter

_____
(centimeters)

Child head diameter

_____
(centimeters)

Highest time-averaged mean blood-flow velocity in the distal internal carotid artery	_____ (millimeters)
Depth of the internal carotid artery (ICA) bifurcation	_____ (millimeters)
Location of the internal carotid artery (ICA) bifurcation	_____
Highest time-averaged mean blood-flow velocity in the middle cerebral artery	_____ (millimeters)
Highest time-averaged mean blood-flow velocity in the middle cerebral artery	_____ (millimeters)
Highest time-averaged mean blood-flow velocity in the middle cerebral artery	_____ (millimeters)
Highest time-averaged mean blood-flow velocity in the posterior cerebral artery	_____ (millimeters)

Scoring
Normal: blood velocities less than 170 centimeters per second in all arteries.
Conditional: blood velocities greater than 170 centimeters per second but less than 200 centimeters per second in all arteries.
Abnormal: blood velocity of 200 centimeters per second or greater in either the internal carotid artery or the middle cerebral artery
Inadequate: if the middle cerebral artery (MCA) velocity cannot be estimated on both sides due to poor signal to noise (S/N) ratio the study is inadequate unless one side shows MCA velocity of greater than or equal to 200 centimeters per second.

Imaging Trans Cranial Doppler Ultrasonography - TCDI (PhenX protocol PX0821002 unless stated otherwise)

Imaging Transcranial Doppler Ultrasonography
Identifying Intracranial Landmarks and Major Cerebral Arteries
Krejza et al. (2000) provide standard parameters for the visualization of the anterior, middle, and posterior cerebral arteries through the temporal acoustic window in the thin temporal region of the skull.
Recording Imaging Transcranial Doppler Ultrasonography Results
Examiners should record the highest time-averaged mean blood-flow velocity using a 3-millimeter sample volume placed at the point of highest velocity as determined by color aliasing artifacts in the following arteries:
*middle cerebral artery,
*distal internal carotid artery,
*anterior and posterior cerebral arteries, and
*basilar artery.
Angle-corrected mean velocities can be obtained by automatic or manual tracing of the Doppler waveform. Uncorrected flow velocities are calculated for each artery as the product of angle-corrected velocities and the cosine of the recorded angle of insonation based on the Doppler equation.

Angle-corrected mean velocities by automatic tracing of the Doppler waveform.	_____ (centimeters per second)

Angle-corrected mean velocities by manual tracing of the Doppler waveform.	_____ (centimeters per second)
Highest time-averaged mean blood-flow velocity in the anterior cerebral artery	_____ (millimeters)
Highest time-averaged mean blood-flow velocity in the basilar artery	_____ (millimeters)
Highest time-averaged mean blood-flow velocity in the distal internal carotid artery	_____ (millimeters)
Highest time-averaged mean blood-flow velocity in the middle cerebral artery.	_____ (millimeters)
Highest time-averaged mean blood-flow velocity in the posterior cerebral artery	_____ (millimeters)

Scoring of Uncorrected Flow Velocities
Normal: blood velocities less than 165 centimeters per second in all arteries.
Conditional: blood velocities greater than 165 centimeters per second but less than 200 centimeters per second in all arteries.
Abnormal: blood velocity of 200 centimeters per second or greater in either the internal carotid artery or the middle cerebral artery.

Disability due to mental health symptoms

The symptoms have disrupted your social life / leisure activities	◯ Not at all ◯ 1 ◯ mildly ◯ 3 ◯ 4 ◯ Moderate ◯ 6 ◯ 7 ◯ Markedly ◯ 9 ◯ Extremely (PX630801)
The symptoms have disrupted your family life / home responsibilities	◯ Not at all ◯ 1 ◯ mildly ◯ 3 ◯ 4 ◯ Moderate ◯ 6 ◯ 7 ◯ Markedly ◯ 9 ◯ Extremely (PX630801)

On how many days in the last week did your symptoms cause you to miss school or work or leave you unable to carry out your normal daily responsibilities?	_____ (days | | PX630801)
On how many days in the last week did you feel so impaired by your symptoms, that even though you went to school or work, your productivity was reduced?	_____ (days | | PX630801)

Impairment (Adolescent)

Does this mean you currently have no health insurance or health coverage plan? In answering this question, please exclude plans that pay for only one type of service (such as, nursing home care, accidents, family planning, or dental care) and plans that only provide extra cash when hospitalized.	◯ I do NOT have health insurance ◯ I HAVE some kind of health insurance (PX011502)
In general, how much of a problem do you think you have with: getting into trouble?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
In general, how much of a problem do you think you have with: getting along with your mother/mother figure.	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
In general, how much of a problem do you think you have with: getting along with your father/father figure.	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
In general, how much of a problem do you think you have with: feeling unhappy or sad?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
How much of a problem would you say you have with your behavior at school? (or at your job)	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)

How much of a problem would you say you have with having fun?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
How much of a problem would you say you have getting along with adults other than (your mother and/or your father)?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
How much of a problem do you have with feeling nervous or afraid?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
How much of a problem do you have getting along with your sister(s) and/or brother(s)?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
How much of a problem do you have getting along with other kids your age?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
How much of a problem would you say you have getting involved in activities like sports or hobbies?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)
How much of a problem would you say you have with your school work (doing your job)?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)

How much of a problem would you say you have with your behavior at home?	◯ 0- No problem ◯ 1 ◯ 2 - Some problem ◯ 3 ◯ 4 - Very bad problem ◯ 5 - Not applicable/Don't know (PX0610101)

Scoring:
Responses are summed to give a total score. Scores can range from 0 to 52 with higher scores indicating more impairment.

Impairment (Adult)

WHODAS 2.0
This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.
Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please select only one response.

Standing for long periods such as 30 minutes?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Taking care of your household responsibilities?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (Hours | | PX0610102)
Learning a new task, for example, learning how to get to a new place?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
How much of a problem did you have joining in community activities (for example, festivities, religious, or other activities) in the same way as anyone else can?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
How much have you been emotionally affected by your health problems?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)

Concentrating on doing something for ten minutes?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Walking a long distance such as a kilometer [or equivalent]?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Washing your whole body?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Getting dressed?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Dealing with people you do not know?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Maintaining a friendship?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Your day-to-day work?	◯ None ◯ Mild ◯ Moderate ◯ Severe ◯ Extreme or cannot do (PX0610102)
Overall, in the past 30 days, how many days were these difficulties present?	_____ (Days | | PX0610102)
In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	_____ (Days | | PX0610102)

In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	_____ (Days | | PX0610102)

Scoring:
There are two basic options for computing the summary scores for the WHODAS 2.0 short version.
Simple:
The scores assigned to each of the items-"none" (1), "mild" (2) "moderate" (3), "severe" (4) and "extreme" (5) -are summed. This method is referred to as simple scoring because the scores from each of the items are simply added up without recoding or collapsing of response categories; thus, there is no weighting of individual items. This approach is practical to use as a hand-scoring approach and may be the method of choice in busy clinical settings or in paper-pencil interview situations. As a result, the simple sum of the scores of the items across all domains constitutes a statistic that is sufficient to describe the degree of functional limitations.
Complex:
The more complex method of scoring is called "item-response-theory" (IRT)-based scoring. It takes into account multiple levels of difficulty for each WHODAS 2.0 item. It takes the coding for each item response as "none," "mild," "moderate," "severe," and "extreme" separately and then uses an algorithm to determine the summary score by differentially weighting the items and the levels of severity. The SPSS algorithm is available from WHO. The scoring has three steps:
? Step 1 - Summing of recoded item scores within each domain.
? Step 2 - Summing of all six domain scores.
? Step 3 - Converting the summary score into a metric ranging from 0 to 100 (where 0 = no disability; 100 = full disability).

Motor and attentional impulsivity (immediate and delayed)

A target stimulus is a 5-digit number that is identical to the preceding number. Responses to target stimuli are recorded as correct detections. How many correct detections were made by the participant?	_____ (PX530602)
A filler stimulus is a random 5-digit number that appears whenever a target or catch trial is not scheduled to appear. Responses to filler stimuli are recorded as filler errors. How many filler errors were made by the participant?	_____ (PX530602)
What is the rate of correct detections?	_____ (PX530602)
What is the rate of commision error responses to catch stimuli?	_____ (PX530602)
What is the rate of filler errors?	_____ (PX530602)
What are the parametric and non-parametric indices or stimulus discriminability?	_____ (PX530602)
What are the parametric and non-parametric indices of response bias (i.e. liberal or conservative resppon	_____ (PX530602)

Pediatric school performance

1. What is your child's current grade?

_____
(PX0840201)

2. What is your child's current age? Years

_____
(years | | PX0840201)

2A. What is your child's current age? Months

_____
(years | | PX0840201)

3. Has your child ever been held back or repeated a grade?

◯ Yes
◯ No
(PX0840201)

3A. How many grades?

◯ 1
◯ 2
◯ 3 or more
(PX0840201)

3B. Which grade(s)? (List up to 3 most recent grades - use a COMMA in between grades if more than one)

_____
(PX0840201)

4. Does your child have any accommodations because of learning differences? Check all that apply

☐ Special Education Services
☐ 504 Plan
☐ IEP-individualized education plan
☐ Special tutoring or classes not available to regular students
☐ Other; describe below
☐ My child does not receive any accommodation for learning differences
(PX0840201)

Does your child have any accommodations because of learning differences? Other

_____
(PX0840201)