Subject ID

Patient Reported Outcome Form

Baseline

Final Version 1.0, 2/3/2020

Please answer the following questions to the best of your ability and return the completed form to the study coordinator when you are done.

GENERAL INFORMATION

Date form completed: |__|__| / |__|__| / |__|__|__|__|

Month Day Year

DEMOGRAPHICS

Please tell us about yourself.

1. What is your current marital status?

   ❒ Married

   ❒ Living as married (including living with a partner)

   ❒ Divorced or separated

   ❒ Widowed

   ❒ Never married

2. What is the highest grade or level of school you have completed or the highest degree you have received?

   ❒ Less than high school

   ❒ Some high school

   ❒ High school graduate or GED equivalent

   ❒ Some college or vocational training

   ❒ College graduate

   ❒ Some graduate school or professional school

   ❒ Graduate or professional degree

3. We would like to know about what you do – are you working, looking for work, retired, keeping house, or what?

   ❒ Working now

   ❒ Only temporarily laid off, sick leave, or maternity leave

   ❒ Looking for work, unemployed

   ❒ Retired

   ❒ Disabled, permanently or temporarily

   ❒ Keeping house

   ❒ Student

   ❒ Other, specify: _____

4. What is your approximate yearly household income? Include income from all sources.

   ❒ $25,000 and under

   ❒ $25,001 - $50,000

   ❒ $50,0001 - $75,000

   ❒ $75,0001 - $100,000

   ❒ >$100,000

5. Without giving exact dollars, how would you describe your household's financial situation right now? (*read the 4 choices and mark the option closest to your situation*). Would you say that...

   ❒ After paying the bills, you still have enough money for special things that you want.

   ❒ You have enough money to pay the bills, but little spare money to buy extra or special things.

   ❒ You have money to pay bills, but only because you have to cut back on things.

   ❒ You are having difficulty paying the bills, no matter what you do.

6. What type of Health Insurance Coverage do you have? Please check all that apply.

   ❒ Private Health Insurance

   ❒ Medicare

   ❒ Medicaid, please specify the state specific Medicaid: _____

   ❒ SCHIP (CHIP/Children Health Insurance Program)

   ❒ Military Health Care (TRICARE/VA/CHAMP-VA)

   ❒ Indian Health Service

   ❒ State Sponsored Health Plan

   ❒ Other – Government program

   ❒ No coverage of any type

   ❒ Don’t know

YOUR PAIN HISTORY

1. In the <u>past 12 months</u>, how many sickle cell pain attacks (crises) did you have?

   ❒ I did not have a pain attack 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) → ***skip to YOUR PAIN HISTORY Question 6***

   ❒ 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. How severe was your pain during your last pain attack (crisis)? Choose a number from 0 to 10 below, where 0 is no pain and 10 is the worst pain imaginable.

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Pain Imaginable

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) did you have?

   ❒ 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

6. Think about your pain in the past 7 days, and answer the following questions.

		Never	Rarely	Sometimes	Often	Always
a.	How often did you have very severe pain?	❒	❒	❒	❒	❒
b.	How often did you have pain so bad that it was hard to finish what you were doing?	❒	❒	❒	❒	❒

7. Think about how your pain felt in the past 7 days, and answer the following questions.

		Not at all	A little bit	Somewhat	Quite a bit	Very much
a.	Did your pain feel like pins and needles?	❒	❒	❒	❒	❒
b.	Did your pain feel sore?	❒	❒	❒	❒	❒

8. Now think about your pain in the past 6 months, and answer the following questions.

		Never	Rarely	Sometimes	Often	Always
a.	How often did you have very severe pain?	❒	❒	❒	❒	❒
b.	How often did you have pain so bad that it was hard to finish what you were doing?	❒	❒	❒	❒	❒

MEDICATION SELF-EFFICACY

Think about when you take hydroxyurea when answering the following questions:

Please respond to each statement below by marking one box per row.

CURRENT Level of Confidence (confidence is how sure you are about each statement)		I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
a.	I can follow directions when my doctor changes my medications	❒	❒	❒	❒	❒
b.	I can take my medication when I am working or away from home	❒	❒	❒	❒	❒
c.	I can take my medication when there is a change in my usual day (unexpected things happen)	❒	❒	❒	❒	❒
d.	I can manage my medication without help	❒	❒	❒	❒	❒
e.	I can remember to take my medication as prescribed	❒	❒	❒	❒	❒
f.	I can use technology to help me manage my medication and treatments (for example: to get information, avoid side-effects, schedule reminders)	❒	❒	❒	❒	❒
g.	I can list my medications, including the doses and schedule	❒	❒	❒	❒	❒
h.	I can figure out what treatment I need when my symptoms change	❒	❒	❒	❒	❒

HEALTH LITERACY

		Never	Rarely	Sometimes	Often	Always
a.	How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?	❒	❒	❒	❒	❒

HYDROXYUREA HISTORY

1. Have you ever been prescribed hydroxyurea?

   ❒ Yes

   ❒ No

2. Have you ever filled a hydroxyurea prescription?

   ❒ Yes

   ❒ No → ***skip to END***

3. Are you <u>currently</u> taking hydroxyurea?

   ❒ Yes → ***skip to HYDROXYUREA ADHERENCE Question 1***

   ❒ No

4. What is the reason you discontinued or stopped taking hydroxyurea?

   ❒ Side effects

   ❒ Personal preference

   ❒ Provider decision

   ❒ Didn't work

   ❒ Pregnancy concerns

   ❒ Other reason not listed above, specify _____

   → ***Please answer HYDROXYUREA History Question 4 and skip to END***

HYDROXYUREA ADHERENCE

Please answer the following questions about your use of hydroxyurea in the <u>past 7 days</u> if you are currently taking it.

1. How many days did you take it?

   ❒ 0 day ❒ 1 day ❒ 2 days ❒ 3 days ❒ 4 days ❒ 5 days ❒ 6 days ❒ 7 days

2. How many times per day did you take it? _____ (days)

3. How many pills did you take each time? _____ (pills)

4. How many times did you miss taking a pill? _____ (times missed)

5. How well does hydroxyurea work for you?

   ❒ Well

   ❒ Okay

   ❒ Not well

This is the END of the survey. Please return it to the study coordinator.

Thank you for your participation.