

Subject ID



Patient Reported Outcome Form

24 Weeks

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

YOUR PAIN HISTORY

1. In the past 12 months, 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 Question 6 in YOUR PAIN HISTORY section**
- 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
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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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How often did you have pain so bad that it was hard to finish what you were doing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	Did your pain feel sore?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How often did you have pain so bad that it was hard to finish what you were doing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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
b.	I can take my medication when I am working or away from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I can take my medication when there is a change in my usual day (unexpected things happen)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I can manage my medication without help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	I can remember to take my medication as prescribed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	I can use technology to help me manage my medication and treatments (for example: to get information, avoid side-effects, schedule reminders)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g.	I can list my medications, including the doses and schedule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h.	I can figure out what treatment I need when my symptoms change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

HYDROXYUREA HISTORY

Question 1 in HYDROXYUREA HISTORY section is only asked at baseline.

2. Have you ever filled a hydroxyurea prescription?

Yes

No → **skip to ENGAGEMENT WITH THE InCharge Health App section**

3. Are you currently taking hydroxyurea?

Yes → **skip to Question 1 in HYDROXYUREA ADHERENCE section**

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 Question 4 in the HYDROXYUREA HISTORY section, then skip to ENGAGEMENT WITH THE InCharge Health App section.

HYDROXYUREA ADHERENCE

Please answer the following questions about your use of hydroxyurea in the past 7 days 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

ENGAGEMENT WITH THE *InCharge Health App*

1. Is the app interesting to use?

Not interesting at all

Mostly uninteresting

Ok, neither interesting nor uninteresting

Moderately interesting

Very interesting

2. How often did you use the app these last 3 months?

Every day

Two to three times per week

Once a week

Once a month

Did not use at all

3. Which features of the app did you find most useful (rank in order of importance)?

		Most important 1	2	3	4	5	6	7	Least important 8
a.	Reminders to take hydroxyurea (text messages)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	A person you chose as a partner knowing you did not take the medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	A person you chose as a partner knowing you were in the hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	Information about hydroxyurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	Connection with other people with sickle cell disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	Access to your medical chart	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g.	The 7-day streaks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h.	The graphs about my pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. How much do you agree with the following statements?

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a.	The app helped me remember to take hydroxyurea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	The app helped me learn about sickle cell disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	The app helped me connect with other people with sickle cell disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	The app helped me connect to doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	The app helped me better track my treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	I plan to continue to use the app after the study ends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Ease of use: How easy is it to learn how to use the app; how clear are the menu labels/icons and instructions?

- No/limited instructions; menu labels/icons are confusing; complicated
- Usable after a lot of time and effort
- Usable after a lot of time and effort
- Easy to learn how to use the app
- Able to use app immediately; intuitive; simple

6. What other comments would you have about the app?

7. Do you have any suggestions to improve the app?

8. Did you have any problems when using the app?

9. Anything else you would like to say?

***This is the END of the survey. Please return it to the study coordinator.
Thank you for your participation.***