Patient Registration Form

Patient ID
{[patient_id] text}

_____

Section A

By entering this form into the DMS, you are entering this patient subject into the SCDIC Care Redesign database. The REDCap patient reported outcome survey is accessible after the consent date has been entered. Demographics should be completed for consented subjects only.

1. The subject provided signed consent to participate in the Care Redesign study on:
{[s1f0qa01] text date_mdy}

_____

patient consent yes

_____

{[patient_consent_yes] calc}

1a. Assent form signed (minors only)
{[s1f0qa01a] checkbox}

☐ , {1,}

2. The subject completed the patient reported outcome survey via the following mode:
{[s1f0qa03] radio}

◯ {1} Self-administered; hard copy
◯ {2} Self-administered; online entry
◯ {3} Interview; hard copy
◯ {4} Interview; online entry
◯ {5} Interview; phone
(Check one.)

3. Clinic Location:
{[s1f0qa02] dropdown}

◯ {1} St. Jude Children's Research Hospital
◯ {2} Methodist University Hospital
◯ {3} Baptist Health Care
◯ {4} Duke Adult Sickle Cell Clinic
◯ {5} UI Hospital & Health Sciences System, Sickle Cell Center
◯ {6} UI Hospital & Health Sciences System, Pediatric Department
◯ {7} OSF Healthcare/Children's Hospital of Illinois
◯ {8} Sinai Health System
◯ {9} Lawndale Christian Health Center
◯ {10} UCSF Benioff Children's Hospital Oakland
◯ {11} UC Davis
◯ {12} Mount Sinai Hospital
◯ {13} St. Louis Children's Hospital Pediatric
◯ {14} Barnes Jewish Hospital Hematology
◯ {15} Christian Hospital Northeast-Hematology
◯ {16} Augusta University Adult Center for Blood Disorders
◯ {17} AU Pediatric Hem/Onc
◯ {18} AU Macon Outreach Clinic
◯ {19} AU Sylvester Outreach Clinic
◯ {20} AU Savannah Outreach Clinic
◯ {21} Adult Sickle Cell Clinic
◯ {22} Pediatric Sickle Cell Clinic
◯ {23} Duke Pediatric Sickle Cell Clinic

Section B

Patient Demographics for Consented Subjects Only:

1. Date of birth
{[s1f0qb01] text date_mdy}
{Branching logic (show if): [s1f0qa01] ""}

_____

2. Race
{[s1f0qb02] checkbox}
{Branching logic (show if): [s1f0qa01] ""}

☐ {1} American Indian or Alaska Native
☐ {2} Asian
☐ {3} Black or African American
☐ {4} Native Hawaiian or Pacific Islander
☐ {5} White
(Check all that apply.)

3. Ethnicity
{[s1f0qb03] radio}
{Branching logic (show if): [s1f0qa01] ""}

◯ {1} Hispanic or Latino
◯ {2} Not Hispanic or Latino
(Check one.)

4. Biological Sex
{[s1f0qb04] radio}
{Branching logic (show if): [s1f0qa01] ""}

◯ {1} Male
◯ {2} Female

5. Zip code of primary residence
{[s1f0qb05] text zipcode}
{Branching logic (show if): [s1f0qa01] ""}

_____

6. Is this patient enrolled in the Registry? (If patient is not enrolled in the Registry at the time of Care Redesign enrollment, enroll patient at Week 12 visit)
{[s1f0qb06] yesno}
{Branching logic (show if): [s1f0qa01] ""}

◯ Yes
◯ No

6a. If 'Yes', provide Registry Subject ID:
{[s1f0qb06a] text}
{Branching logic (show if): [s1f0qa01] "" and [s1f0qb06] =1}

_____

Patient Reported Outcome Form

Please complete the survey below.

Thank you!

GENERAL INFORMATION

Date form completed:
{[s1f3qa01] text date_mdy}

_____

DEMOGRAPHICS SECTION

Please tell us about yourself.

1. What is your current marital status?
{[s1f3qb01] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ {1} Married
◯ {2} Living as married (including living with a partner)
◯ {3} Divorced or separated
◯ {4} Widowed
◯ {5} Never married

2. What is the highest grade or level of school you have completed or the highest degree you have received?
{[s1f3qb02] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ {1} Less than high school
◯ {2} Some high school
◯ {3} High school graduate or GED equivalent
◯ {4} Some college or vocational training
◯ {5} College graduate
◯ {6} Some graduate school or professional school
◯ {7} 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?
{[s1f3qb03] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ {1} Working now
◯ {2} Only temporarily laid off, sick leave, or maternity leave
◯ {3} Looking for work, unemployed
◯ {4} Retired
◯ {5} Disabled, permanently or temporarily
◯ {6} Keeping house
◯ {7} Student
◯ {8} Other

3a. If 'Other', specify:
{[s1f3qb03a] text}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f3qb03] = 8}

_____

4. What is your approximate yearly household income? Include income from all sources.
{[s1f3qb08] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ {1} $25,000 and under
◯ {2} $25,001 - $50,000
◯ {3} $50,001 - $75,000
◯ {4} $75,001 - $100,000
◯ {5} >$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...
{[s1f3qb05] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ {1} After paying the bills, you still have enough money for special things that you want.
◯ {2} You have enough money to pay the bills, but little spare money to buy extra or special things.
◯ {3} You have money to pay bills, but only because you have to cut back on things.
◯ {4} You are having difficulty paying the bills, no matter what you do.

6. What type of Health Insurance Coverage do you have?
{[s1f3qb06] checkbox}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

☐ {1} Private Health Insurance
☐ {2} Medicare
☐ {3} Medicaid
☐ {4} SCHIP (CHIP/Children Health Insurance Program)
☐ {5} Military Health Care (TRICARE/VA/CHAMP-VA)
☐ {6} Indian Health Service
☐ {7} State Sponsored Health Plan
☐ {8} Other - Government program
☐ {9} No Coverage of any type
☐ {99} Don't know
(Please check all that apply.)

6a. If 'Medicaid', please specify the state specific Medicaid:
{[s1f3qb06a] text}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f3qb06(8)] =1}

_____

YOUR PAIN HISTORY

1. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
{[s1f3qc01] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {1} I did not have a pain attack in the past 12 months
◯ {2} 1
◯ {3} 2
◯ {4} 3
◯ {5} 4 or more

2. When was your last pain attack (crisis)?
{[s1f3qc02] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {1} I've never had a pain attack (crisis)
◯ {2} More than 5 years ago
◯ {3} 1-5 years ago
◯ {4} 7-11 months ago
◯ {5} 1-6 months ago
◯ {6} 1-3 weeks ago
◯ {7} Less than a week ago
◯ {8} 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.
{Branching logic (show if): ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1') and [s1f3qc02]>1}

No pain
s1f3qc03
Worst pain imaginable

{Branching logic (show if): ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1') and [s1f3qc02]>1}

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.
{[s1f3qc03] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {0} 0 ◯ {1} 1 ◯ {2} 2
◯ {3} 3 ◯ {4} 4 ◯ {5} 5
◯ {6} 6 ◯ {7} 7 ◯ {8} 8
◯ {9} 9 ◯ {10} 10

4. How much did your last pain attack (crisis) interfere with your life?
{[s1f3qc04] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {1} I've never had a pain attack (crisis)
◯ {2} Not at all, I did everything I usually do
◯ {3} I had to cut down on some things I usually do
◯ {4} I could not do most things I usually do
◯ {5} I could not take care of myself and needed some help from family or friends
◯ {6} 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?
{[s1f3qc05] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {1} I've never had a pain attack (crisis)
◯ {2} Less than 1 hour
◯ {3} 1-12 hours
◯ {4} 13-23 hours
◯ {5} 1-3 days
◯ {6} 4-6 days
◯ {7} 1-2 weeks
◯ {8} More than 2 weeks

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

	{1} Never	{2} Rarely	{3} Sometimes	{4} Often	{5} Always
a. How often did you have very severe pain? {[s1f3qc06a] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	◯	◯	◯	◯	◯
b. How often did you have pain so bad that it was hard to finish what you were doing? {[s1f3qc06b] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	◯	◯	◯	◯	◯

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

{1} Not at all	{2} A little bit	{3} Somewhat	{4} Quite a bit	{5} Very much

a. Did your pain feel like pins and needles? {[s1f3qc07a] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
b. Did your pain feel sore? {[s1f3qc07b] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○

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

	{1} Never	{2} Rarely	{3} Sometimes	{4} Often	{5} Always
a. How often did you have very severe pain? {[s1f3qc08a] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
b. How often did you have pain so bad that it was hard to finish what you were doing? {[s1f3qc08b] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○

MEDICATION SELF-EFFICACY

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

CURRENT level of confidence

	{1} I am not at all confident	{2} I am a little confident	{3} I am somewhat confident	{4} I am quite confident	{5} I am very confident

a. I can follow directions when my doctor changes my medications {[s1f3qda] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
b. I can take my medication when I am working or away from home {[s1f3qdb] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
c. I can take my medication when there is a change in my usual day (unexpected things happen) {[s1f3qdc] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
d. I can manage my medication without help {[s1f3qdd] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
e. I can remember to take my medication as prescribed {[s1f3qde] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○

f. I can use technology to help me manage my medication and treatments (for example: to get information, avoid side-effects, schedule reminders) {[s1f3qdf] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
g. I can list my medications, including the doses and schedule {[s1f3qdg] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
h. I can figure out what treatment I need when my symptoms change {[s1f3qdh] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○

HEALTH LITERACY

	{1} Never	{2} Rarely	{3} Sometimes	{4} Often	{5} 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? {[s1f3qea] radio} {Branching logic (show if): [event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○

HYDROXYUREA History

1. Have you ever been prescribed hydroxyurea?
{[s1f3qf01] yesno}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ Yes ◯ No

2. Have you ever filled a hydroxyurea prescription?
{[s1f3qf02] yesno}
{Branching logic (show if): ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

◯ Yes ◯ No

3. Are you currently taking hydroxyurea?
{[s1f3qf03] yesno}
{Branching logic (show if): [s1f3qf02] =1 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

◯ Yes ◯ No

4. What is the reason you discontinued or stopped taking hydroxyurea?
{[s1f3qf04] radio}
{Branching logic (show if): [s1f3qf03] = 0 and [s1f3qf02] =1 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

◯ {1} Side effects
◯ {2} Personal preference
◯ {3} Provider decision
◯ {4} Didn't work
◯ {5} Pregnancy concerns
◯ {6} Other reason not listed above (and specify)

4a. If 'Other reason', specify:
{[s1f3qf04a] text}
{Branching logic (show if): [s1f3qf04] = 6 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

_____

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?
{[s1f3qg01] radio}
{Branching logic (show if): [s1f3qf03] =1 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

◯ {0} 0 day
◯ {1} 1 day
◯ {2} 2 days
◯ {3} 3 days
◯ {4} 4 days
◯ {5} 5 days
◯ {6} 6 days
◯ {7} 7 days

2. How many times per day did you take it?
{[s1f3qg02] text integer}
{Branching logic (show if): [s1f3qf03] =1 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

_____

3. How many pills did you take each time?
{[s1f3qg03] text float}
{Branching logic (show if): [s1f3qf03] =1 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

_____

4. How many times did you miss taking a pill?
{[s1f3qg04] text integer}
{Branching logic (show if): [s1f3qf03] =1 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

_____

5. How well does Hydroxyurea work for you?
{[s1f3qg05] radio}
{Branching logic (show if): [s1f3qf03] =1 and ([event-name] = 'baseline_arm_1' or [event-name] = '24_weeks_arm_1')}

◯ {1} Well
◯ {2} Okay
◯ {3} Not well

ENGAGEMENT WITH THE InCharge Health APP

1. Is the app interesting to use?
{[s1f3qh01] radio}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {1} Not interesting at all
◯ {2} Mostly uninteresting
◯ {3} OK, neither interesting nor uninteresting
◯ {4} Moderately interesting
◯ {5} Very interesting

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

{[s1f3qh02] radio}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {1} Every day
◯ {2} Two to three times per week
◯ {3} Once a week
◯ {4} Once a month
◯ {5} Did not use at all

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

	{1} Most important 1	{2} 2	{3} 3	{4} 4	{5} 5	{6} 6	{7} 7	{8} Least important 8
a. Reminders to take hydroxyurea (text messages) {[s1f3qh03_a] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	◯	◯	◯	◯	◯	◯	◯	◯
b. A person you chose as a partner knowing you did not take the medicine {[s1f3qh03_b] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	◯	◯	◯	◯	◯	◯	◯	◯

c. A person you chose as a partner knowing you were in the hospital {[s1f3qh03_c] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○	○	○	○
d. Information about hydroxyurea {[s1f3qh03_d] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○	○	○	○
e. Connection with other people with sickle cell disease {[s1f3qh03_e] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○	○	○	○
f. Access to your medical chart {[s1f3qh03_f] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○	○	○	○
g. The 7-day streaks {[s1f3qh03_g] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○	○	○	○
h. The graphs about my pain {[s1f3qh03_h] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○	○	○	○

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

	{1} Strongly disagree	{2} Disagree	{3} Neutral	{4} Agree	{5} Strongly agree
a. The app helped me remember to take hydroxyurea {[s1f3qh04a] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
b. The app helped me learn about sickle cell disease {[s1f3qh04b] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
c. The app helped me connect with other people with sickle cell disease {[s1f3qh04c] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
d. The app helped me connect to doctors {[s1f3qh04d] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
e. The app helped me better track my treatment {[s1f3qh04e] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○
f. I plan to continue to use the app after the study ends {[s1f3qh04f] radio} {Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}	○	○	○	○	○

5. Ease of use: How easy is it to learn how to use the app; how clear are the menu labels/icons and instructions?
{[s1f3qh05] radio}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}

◯ {1} No/limited instructions; menu labels/icons are confusing; complicated
◯ {2} Useable after a lot of time and effort
◯ {3} Useable after some time and effort
◯ {4} Easy to learn how to use the app
◯ {5} Able to use app immediately; intuitive; simple

6. What other comments would you have about the app?
{[s1f3qh06] textarea}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}

_____

7. Do you have any suggestions to improve the app?
{[s1f3qh07] textarea}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}

_____

8. Did you have any problems when using the app?
{[s1f3qh08] textarea}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}

_____

9. Anything else you would like to say?
{[s1f3qh09] textarea}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1'}

_____

Patient Medical Record Abstraction Form

Name of Abstractor:
{[s1f1q00] text}
_____

1. DATE OF ABSTRACTION:
{[s1f1q01] text date_mdy}
_____

2. Confirmed enrollment diagnosis: (CHECK ONLY ONE).
DIAGNOSIS MUST BE SUPPORTED BY SOURCE DOCUMENTATION .

Diagnosis:
{[s1f1q02] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ {1} Hb SS or sickle cell anemia
◯ {2} Hb SC disease
◯ {3} Hb S beta^0 thalassemia
◯ {4} Hb S beta^+ thalessemia
◯ {5} Hb S hereditary persistence of fetal Hb (S/HPFH)
◯ {6} Hb SE
◯ {7} Hb SD
◯ {8} Hb SO

3. Height (CM)
{[s1f1q03] checkbox}
☐ {1} Not in record

Measurements
{[s1f1q03_1] text float}
{Branching logic (show if): [s1f1q03(1)]= 0}
_____

Date
{[s1f1q03_2] text}
{Branching logic (show if): [s1f1q03(1)]= 0}
_____ (mm/dd/yyyy, enter 99/99/9999 for unknown)

Steady state?
{[s1f1q03_3] yesno}
{Branching logic (show if): [s1f1q03(1)]= 0}
◯ Yes ◯ No

4. Weight (KG)
{[s1f1q04] checkbox}
☐ {1} Not in record

Measurements
{[s1f1q04_1] text float}
{Branching logic (show if): [s1f1q04(1)]= 0}
_____

Date
{[s1f1q04_2] text}
{Branching logic (show if): [s1f1q04(1)]= 0}
_____ (mm/dd/yyyy, enter 99/99/9999 for unknown)

Steady state?
{[s1f1q04_3] yesno}
{Branching logic (show if): [s1f1q04(1)]= 0}
◯ Yes ◯ No

5. Temperature (Celsius)
{[s1f1q05] checkbox}
☐ {1} Not in record

Measurements
{[s1f1q05_1] text float}
{Branching logic (show if): [s1f1q05(1)]= 0}
_____

Date
{[s1f1q05_2] text}
{Branching logic (show if): [s1f1q05(1)]= 0}

_____
(mm/dd/yyyy, enter 99/99/9999 for unknown)

Steady state?
{[s1f1q05_3] yesno}
{Branching logic (show if): [s1f1q05(1)]= 0}

◯ Yes ◯ No

6. Heart Rate (Beats/Minute)
{[s1f1q06] checkbox}

☐ {1} Not in record

Measurements
{[s1f1q06_1] text float}
{Branching logic (show if): [s1f1q06(1)]= 0}

_____

Date
{[s1f1q06_2] text}
{Branching logic (show if): [s1f1q06(1)]= 0}

_____
(mm/dd/yyyy, enter 99/99/9999 for unknown)

Steady state?
{[s1f1q06_3] yesno}
{Branching logic (show if): [s1f1q06(1)]= 0}

◯ Yes ◯ No

7. Respiration Rate (Breaths/Minute)
{[s1f1q07] checkbox}

☐ {1} Not in record

Measurements
{[s1f1q07_1] text float}
{Branching logic (show if): [s1f1q07(1)]= 0}

_____

Date
{[s1f1q07_2] text}
{Branching logic (show if): [s1f1q07(1)]= 0}

_____
(mm/dd/yyyy, enter 99/99/9999 for unknown)

Steady state?
{[s1f1q07_3] yesno}
{Branching logic (show if): [s1f1q07(1)]= 0}

◯ Yes ◯ No

8. Oxygen Saturation Level (SpO2)
{[s1f1q08] checkbox}

☐ {1} Not in record

Measurements
{[s1f1q08_1] text float}
{Branching logic (show if): [s1f1q08(1)]= 0}

_____
(%)

Date
{[s1f1q08_2] text}
{Branching logic (show if): [s1f1q08(1)]= 0}

_____
(mm/dd/yyyy, enter 99/99/9999 for unknown)

Steady state?
{[s1f1q08_3] yesno}
{Branching logic (show if): [s1f1q08(1)]= 0}

◯ Yes ◯ No

9. Blood Pressure
{[s1f1q09] checkbox}

☐ {1} Not in record

Measurements
{Branching logic (show if): [s1f1q09(1)]= 0}

Systolic
{[s1f1q09_1] text float}
{Branching logic (show if): [s1f1q09(1)]= 0}

_____

Diastolic
{[s1f1q09_2] text float}
{Branching logic (show if): [s1f1q09(1)]= 0}

_____

ON ANTI-HYPERTENSIVE MEDS?
{[s1f1q09_3] yesno}
{Branching logic (show if): [s1f1q09(1)]= 0}

◯ Yes ◯ No

Date
{[s1f1q09_4] text}
{Branching logic (show if): [s1f1q09(1)]= 0}

_____
(mm/dd/yyyy, enter 99/99/9999 for unknown)

Steady state?
{[s1f1q09_5] yesno}
{Branching logic (show if): [s1f1q09(1)]= 0}

◯ Yes ◯ No

10. Hydroxyurea history

a. Start date
{[s1f1q10a] text}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

_____
(mm/yyyy, enter 99/9999 for unknown)

b. MTD dose
{[s1f1q10b] text integer}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

_____

MTD dose units
{[s1f1q10c_u] radio}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ {1} mg/kg
◯ {2} mg/day
◯ {3} mg/kg/day

c. Current dose

Mg/kg/day
{[s1f1q10c_1] text integer}

_____

OR

Mg/day
{[s1f1q10c_2] text integer}

_____

d. Was dose held since last study visit?
{[s1f1q10d] yesno}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1'}

◯ Yes ◯ No

If so, reason
{[s1f1q10d_rsn] radio}
{Branching logic (show if): [s1f1q10d] = 1}

◯ {1} Neutropenia
◯ {2} Reticulocytopenia
◯ {3} Thrombocytopenia

11. Has the subject ever used Endari? {[s1f1q11b] radio}	◯ {1} Yes ◯ {0} No
a. Start date {[s1f1q11b_a] text} {Branching logic (show if): [s1f1q11b]= '1'}	_____ (mm-yyyy, enter 99-9999 for unknown)
b. Stop/last date {[s1f1q11b_b1] checkbox} {Branching logic (show if): [s1f1q11b]= '1'}	☐ {1} Currently Using
b. Stop/last date {[s1f1q11b_b] text} {Branching logic (show if): [s1f1q11b]= '1' and [s1f1q11b_b1(1)] = 0}	_____ (mm-yyyy, enter 99-9999 for unknown)
c. Total duration of use {[s1f1q11b_c] text float} {Branching logic (show if): [s1f1q11b]= '1'}	_____ (Enter 0 if unknown)
Unit {[s1f1q11b_c1] radio} {Branching logic (show if): [s1f1q11b]= '1' and [s1f1q11b_c] > 0}	◯ {1} Months ◯ {2} Years
d. Current dose (g) {[s1f1q11b_d] text float} {Branching logic (show if): [s1f1q11b]= '1'}	_____ ((g) Enter 0 if unknown)
e. Current frequency {[s1f1q11b_e] radio} {Branching logic (show if): [s1f1q11b]= '1'}	◯ {1} Twice a day ◯ {2} Other
12. Has the subject ever used Crizanlizumab? {[s1f1q12b] radio}	◯ {1} Yes ◯ {0} No
a. Start date {[s1f1q12b_a] text} {Branching logic (show if): [s1f1q12b]= '1'}	_____ (mm-yyyy, enter 99-9999 for unknown)
b. Stop/last date {[s1f1q12b_b1] checkbox} {Branching logic (show if): [s1f1q12b]= '1'}	☐ {1} Currently Using
b. Stop/last date {[s1f1q12b_b] text} {Branching logic (show if): [s1f1q12b]= '1' and [s1f1q12b_b1(1)]=0}	_____ (mm-yyyy, enter 99-9999 for unknown)
c. Total duration of use {[s1f1q12b_c] text float} {Branching logic (show if): [s1f1q12b]= '1'}	_____ (Enter 0 if unknown)
Unit {[s1f1q12b_c1] radio} {Branching logic (show if): [s1f1q12b]= '1' and [s1f1q12b_c] > 0}	◯ {1} Months ◯ {2} Years

d. Current dose (g)
{[s1f1q12b_d] text float}
{Branching logic (show if): [s1f1q12b]= '1'}
_____
((g) Enter 0 if unknown)

e. Current frequency
{[s1f1q12b_e] radio}
{Branching logic (show if): [s1f1q12b]= '1'}
◯ {1} Once a month
◯ {2} Other

13. Has the subject ever used Voxelator?
{[s1f1q13b] radio}
◯ {1} Yes ◯ {0} No

a. Start date
{[s1f1q13b_a] text}
{Branching logic (show if): [s1f1q13b]= '1'}
_____
(mm-yyyy, enter 99-9999 for unknown)

b. Stop/last date
{[s1f1q13b_b1] checkbox}
{Branching logic (show if): [s1f1q13b]= '1'}
☐ {1} Currently Using

b. Stop/last date
{[s1f1q13b_b] text}
{Branching logic (show if): [s1f1q13b]= '1' and [s1f1q13b_b1(1)] = 0}
_____
(mm-yyyy, enter 99-9999 for unknown)

c. Total duration of use
{[s1f1q13b_c] text float}
{Branching logic (show if): [s1f1q13b]= '1'}
_____
(Enter 0 if unknown)

Unit
{[s1f1q13b_c1] radio}
{Branching logic (show if): [s1f1q13b]= '1' and [s1f1q13b_c] > 0}
◯ {1} Months ◯ {2} Years

d. Current dose (g)
{[s1f1q13b_d] text float}
{Branching logic (show if): [s1f1q13b]= '1'}
_____
((g) Enter 0 if unknown)

e. Current frequency
{[s1f1q13b_e] radio}
{Branching logic (show if): [s1f1q13b]= '1'}
◯ {1} Once a day
◯ {2} Other

14. Acute Care/Infusion Center (not admitted)
{[s1f1q11] radio}
◯ {1} Yes
◯ {2} No acute care visits since last visit
◯ {3} Not in record

Acute Care 1

a. Visit/Admission Date
{[s1f1q11_1a] text}
{Branching logic (show if): [s1f1q11] =1}
_____
(mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q11_1b] yesno}
{Branching logic (show if): [s1f1q11] =1}
◯ Yes
◯ No

c. Led to an admission? ◯ Yes ◯ No
{[s1f1q11_1c] yesno}
{Branching logic (show if): [s1f1q11] =1}

Acute Care 2

a. Visit/Admission Date
{[s1f1q11_2a] text}
{Branching logic (show if): [s1f1q11_1a] ""} _____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain? ◯ Yes ◯ No
{[s1f1q11_2b] yesno}
{Branching logic (show if): [s1f1q11_1a] ""}

c. Led to an admission? ◯ Yes ◯ No
{[s1f1q11_2c] yesno}
{Branching logic (show if): [s1f1q11_1a] ""}

Acute Care 3

a. Visit/Admission Date
{[s1f1q11_3a] text}
{Branching logic (show if): [s1f1q11_2a] ""} _____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain? ◯ Yes ◯ No
{[s1f1q11_3b] yesno}
{Branching logic (show if): [s1f1q11_2a] ""}

c. Led to an admission? ◯ Yes ◯ No
{[s1f1q11_3c] yesno}
{Branching logic (show if): [s1f1q11_2a] ""}

Acute Care 4

a. Visit/Admission Date
{[s1f1q11_4a] text}
{Branching logic (show if): [s1f1q11_3a] ""} _____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain? ◯ Yes ◯ No
{[s1f1q11_4b] yesno}
{Branching logic (show if): [s1f1q11_3a] ""}

c. Led to an admission? ◯ Yes ◯ No
{[s1f1q11_4c] yesno}
{Branching logic (show if): [s1f1q11_3a] ""}

Acute Care 5

a. Visit/Admission Date
{[s1f1q11_5a] text}
{Branching logic (show if): [s1f1q11_4a] ""}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q11_5b] yesno}
{Branching logic (show if): [s1f1q11_4a] ""}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q11_5c] yesno}
{Branching logic (show if): [s1f1q11_4a] ""}

◯ Yes ◯ No

Acute Care 6

a. Visit/Admission Date
{[s1f1q11_6a] text}
{Branching logic (show if): [s1f1q11_5a] ""}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q11_6b] yesno}
{Branching logic (show if): [s1f1q11_5a] ""}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q11_6c] yesno}
{Branching logic (show if): [s1f1q11_5a] ""}

◯ Yes ◯ No

Acute Care 7

a. Visit/Admission Date
{[s1f1q11_7a] text}
{Branching logic (show if): [s1f1q11_6a] ""}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q11_7b] yesno}
{Branching logic (show if): [s1f1q11_6a] ""}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q11_7c] yesno}
{Branching logic (show if): [s1f1q11_6a] ""}

◯ Yes ◯ No

Acute Care 8

a. Visit/Admission Date
{[s1f1q11_8a] text}
{Branching logic (show if): [s1f1q11_7a] ""}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q11_8b] yesno}
{Branching logic (show if): [s1f1q11_7a] ""}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q11_8c] yesno}
{Branching logic (show if): [s1f1q11_7a] ""}

◯ Yes ◯ No

Acute Care 9

a. Visit/Admission Date
{[s1f1q11_9a] text}
{Branching logic (show if): [s1f1q11_8a] ""}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q11_9b] yesno}
{Branching logic (show if): [s1f1q11_8a] ""}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q11_9c] yesno}
{Branching logic (show if): [s1f1q11_8a] ""}

◯ Yes ◯ No

Acute Care 10

a. Visit/Admission Date
{[s1f1q11_10a] text}
{Branching logic (show if): [s1f1q11_9a] ""}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q11_10b] yesno}
{Branching logic (show if): [s1f1q11_9a] ""}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q11_10c] yesno}
{Branching logic (show if): [s1f1q11_9a] ""}

◯ Yes ◯ No

15. Emergency Department Visit (not admitted)
{[s1f1q12] radio}

◯ {1} Yes
◯ {2} No emergency department visits since last visit
◯ {3} Not in record

Emergency visit 1

a. Visit/Admission Date
{[s1f1q12_1a] text}
{Branching logic (show if): [s1f1q12]= 1}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q12_1b] yesno}
{Branching logic (show if): [s1f1q12]= 1}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q12_1c] yesno}
{Branching logic (show if): [s1f1q12]= 1}

◯ Yes ◯ No

Emergency Visit 2

a. Visit/Admission Date
{[s1f1q12_2a] text}
{Branching logic (show if): [s1f1q12_1a] ""}

_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q12_2b] yesno}
{Branching logic (show if): [s1f1q12_1a] ""}

◯ Yes
◯ No

c. Led to an admission?
{[s1f1q12_2c] yesno}
{Branching logic (show if): [s1f1q12_1a] ""}
◯ Yes ◯ No

Emergency Visit 3

a. Visit/Admission Date
{[s1f1q12_3a] text}
{Branching logic (show if): [s1f1q12_2a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q12_3b] yesno}
{Branching logic (show if): [s1f1q12_2a] ""}
◯ Yes
◯ No

c. Led to an admission?
{[s1f1q12_3c] yesno}
{Branching logic (show if): [s1f1q12_2a] ""}
◯ Yes ◯ No

Emergency Visit 4

a. Visit/Admission Date
{[s1f1q12_4a] text}
{Branching logic (show if): [s1f1q12_3a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q12_4b] yesno}
{Branching logic (show if): [s1f1q12_3a] ""}
◯ Yes
◯ No

c. Led to an admission?
{[s1f1q12_4c] yesno}
{Branching logic (show if): [s1f1q12_3a] ""}
◯ Yes ◯ No

Emergency Visit 5

a. Visit/Admission Date
{[s1f1q12_5a] text}
{Branching logic (show if): [s1f1q12_4a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Was visit for acute pain?
{[s1f1q12_5b] yesno}
{Branching logic (show if): [s1f1q12_4a] ""}
◯ Yes
◯ No

c. Led to an admission?
{[s1f1q12_5c] yesno}
{Branching logic (show if): [s1f1q12_4a] ""}
◯ Yes ◯ No

16. Hospitalization
{[s1f1q13] radio}
◯ {1} Yes
◯ {2} No hospitalizations since last visit
◯ {3} Not in record

First Hospitalization
{Branching logic (show if): [s1f1q13] = 1}

a. Visit/Admission Date
{[s1f1q13_1a] text}
{Branching logic (show if): [s1f1q13] = 1}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Discharge date
{[s1f1q13_1b] text}
{Branching logic (show if): [s1f1q13] = 1}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

c. Was visit for acute pain?
{[s1f1q13_1c] yesno}
{Branching logic (show if): [s1f1q13] = 1}
◯ Yes
◯ No

Second Hospitalization
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_1a] ""}

a. Visit/Admission Date
{[s1f1q13_2a] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_1a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Discharge date
{[s1f1q13_2b] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_1a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

c. Was visit for acute pain?
{[s1f1q13_2c] yesno}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_1a] ""}
◯ Yes
◯ No

Third Hospitalization
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_2a] ""}

a. Visit/Admission Date
{[s1f1q13_3a] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_2a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Discharge date
{[s1f1q13_3b] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_2a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

c. Was visit for acute pain?
{[s1f1q13_3c] yesno}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_2a] ""}
◯ Yes
◯ No

Fourth Hospitalization
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_3a] ""}

a. Visit/Admission Date
{[s1f1q13_4a] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_3a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Discharge date
{[s1f1q13_4b] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_3a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

c. Was visit for acute pain?
{[s1f1q13_4c] yesno}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_3a] ""}
◯ Yes
◯ No

Fifth Hospitalization
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_4a] ""}

a. Visit/Admission Date
{[s1f1q13_5a] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_4a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Discharge date
{[s1f1q13_5b] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_4a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

c. Was visit for acute pain?
{[s1f1q13_5c] yesno}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_4a] ""}
◯ Yes
◯ No

Sixth Hospitalization
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_5a] ""}

a. Visit/Admission Date
{[s1f1q13_6a] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_5a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

b. Discharge date
{[s1f1q13_6b] text}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_5a] ""}
_____ (mm/dd/yyyy (enter 99/99/9999 for unknown))

c. Was visit for acute pain?
{[s1f1q13_6c] yesno}
{Branching logic (show if): [s1f1q13] = 1 AND [s1f1q13_5a] ""}
◯ Yes
◯ No

17. Please list all medications the subject is currently taking.
{[s1f1q14] checkbox}
☐ {1} NONE CURRENTLY BEING USED

Name of Medication
{Branching logic (show if): [s1f1q14(1)]=0}

Medication 1
{[s1f1q14_1] text}
{Branching logic (show if): [s1f1q14(1)]=0}
_____

Medication 2
{[s1f1q14_2] text}
{Branching logic (show if): [s1f1q14_1] ""}
_____

Medication 3
{[s1f1q14_3] text}
{Branching logic (show if): [s1f1q14_2] ""}
_____

Medication 4
{[s1f1q14_4] text}
{Branching logic (show if): [s1f1q14_3] ""}
_____

Medication 5
{[s1f1q14_5] text}
{Branching logic (show if): [s1f1q14_4] ""}
_____

Medication 6
{[s1f1q14_6] text}
{Branching logic (show if): [s1f1q14_5] ""}
_____

Medication 7
{[s1f1q14_7] text}
{Branching logic (show if): [s1f1q14_6] ""}
_____

Medication 8
{[s1f1q14_8] text}
{Branching logic (show if): [s1f1q14_7] ""}
_____

Medication 9
{[s1f1q14_9] text}
{Branching logic (show if): [s1f1q14_8] ""}
_____

Medication 10
{[s1f1q14_10] text}
{Branching logic (show if): [s1f1q14_9] ""}
_____

Medication 11
{[s1f1q14_11] text}
{Branching logic (show if): [s1f1q14_10] ""}
_____

Medication 12
{[s1f1q14_12] text}
{Branching logic (show if): [s1f1q14_11] ""}
_____

Medication 13
{[s1f1q14_13] text}
{Branching logic (show if): [s1f1q14_12] ""}
_____

Medication 14
{[s1f1q14_14] text}
{Branching logic (show if): [s1f1q14_13] ""}
_____

Medication 15
{[s1f1q14_15] text}
{Branching logic (show if): [s1f1q14_14] ""}
_____

Medication 16
{[s1f1q14_16] text}
{Branching logic (show if): [s1f1q14_15] ""}
_____

Medication 17
{[s1f1q14_17] text}
{Branching logic (show if): [s1f1q14_16] ""}
_____

Medication 18
{[s1f1q14_18] text}
{Branching logic (show if): [s1f1q14_17] ""}
_____

Medication 19
{[s1f1q14_19] text}
{Branching logic (show if): [s1f1q14_18] ""}
_____

Medication 20
{[s1f1q14_20] text}
{Branching logic (show if): [s1f1q14_19] ""}
_____

18. Please list transfusion dates.

a. Episodic, simple
{[s1f1q15a] checkbox}
☐ {1} None

ever had
{[s1f1q15a_1] text integer}
{Branching logic (show if): [s1f1q15a(1)]= '0'}
_____ (range (1 - 480))

total units
{[s1f1q15a_2] text float}
{Branching logic (show if): [s1f1q15a(1)]= '0'}
_____ (range (1 -800))

First time
{[s1f1q15a_3] text}
{Branching logic (show if): [s1f1q15a(1)]= '0'}
_____ (mm/yyyy, enter 99/9999 for unknown)

Last time
{[s1f1q15a_4] text}
{Branching logic (show if): [s1f1q15a(1)]= '0'}
_____ (mm/yyyy, enter 99/9999 for unknown)

Frequency
{[s1f1q15a_5] dropdown}
{Branching logic (show if): [s1f1q15a(1)]= '0'}
◯ {1} Less than once/year
◯ {2} About once a year
◯ {3} More than once/year
◯ {99} Unknown

b. Chronic, simple
{[s1f1q15b] checkbox}
☐ {1} None

ever had
{[s1f1q15b_1] text integer}
{Branching logic (show if): [s1f1q15b(1)]= '0'}
_____ (range (1- 480))

total units
{[s1f1q15b_2] text float}
{Branching logic (show if): [s1f1q15b(1)]= '0'}
_____ (range (1-960))

First time
{[s1f1q15b_3] text}
{Branching logic (show if): [s1f1q15b(1)]= '0'}
_____ (mm/yyyy, enter 99/9999 for unknown)

Last time {[s1f1q15b_4] text} {Branching logic (show if): [s1f1q15b(1)]= '0'}	_____ (mm/yyyy, enter 99/9999 for unknown)
Reason stopped {[s1f1q15b_5] radio} {Branching logic (show if): [s1f1q15b(1)]= '0'}	◯ {1} Hemochromatosis ◯ {2} Alloimmunization ◯ {3} Other ◯ {99} Unknown
Frequency {[s1f1q15b_6] dropdown} {Branching logic (show if): [s1f1q15b(1)]= '0'}	◯ {1} Once every 4 weeks ◯ {2} Once every 6 weeks ◯ {3} Once every 8 weeks ◯ {99} Unknown
c. Episodic, exchange {[s1f1q15c] checkbox}	☐ {1} None
# ever had {[s1f1q15c_1] text integer} {Branching logic (show if): [s1f1q15c(1)]= '0'}	_____
First time {[s1f1q15c_2] text} {Branching logic (show if): [s1f1q15c(1)]= '0'}	_____ (mm/yyyy, enter 99/9999 for unknown)
Last time {[s1f1q15c_3] text} {Branching logic (show if): [s1f1q15c(1)]= '0'}	_____ (mm/yyyy, enter 99/9999 for unknown)
Frequency {[s1f1q15c_4] dropdown} {Branching logic (show if): [s1f1q15c(1)]= '0'}	◯ {1} Less than once/year ◯ {2} About once a year ◯ {3} More than once/year ◯ {99} Unknown
Type {[s1f1q15c_5] radio} {Branching logic (show if): [s1f1q15c(1)]= '0'}	◯ {1} Automated ◯ {2} Manual ◯ {99} Unknown
d. Chronic, exchange {[s1f1q15d] checkbox}	☐ {1} None
# ever had {[s1f1q15d_1] text} {Branching logic (show if): [s1f1q15d(1)]= '0'}	_____
First time {[s1f1q15d_2] text} {Branching logic (show if): [s1f1q15d(1)]= '0'}	_____ (mm/yyyy, enter 99/9999 for unknown)
Last time {[s1f1q15d_3] text} {Branching logic (show if): [s1f1q15d(1)]= '0'}	_____ (mm/yyyy, enter 99/9999 for unknown)
Reason stopped {[s1f1q15d_4] radio} {Branching logic (show if): [s1f1q15d(1)]= '0'}	◯ {1} Hemochromatosis ◯ {2} Alloimmunization ◯ {3} Other ◯ {99} Unknown

Frequency {[s1f1q15d_5] dropdown} {Branching logic (show if): [s1f1q15d(1)]= '0'}	◯ {1} Once every 4 weeks ◯ {2} Once every 6 weeks ◯ {3} Once every 8 weeks ◯ {99} Unknown
Type {[s1f1q15d_6] radio} {Branching logic (show if): [s1f1q15d(1)]= '0'}	◯ {1} Automated ◯ {2} Manual ◯ {99} Unknown
Please list hydroxyurea refill {[refill] checkbox}	☐ {1} Patient did not fill any hydroxyurea prescriptions since last visit
Hydroxyurea refill 1 {Branching logic (show if): [refill(1)] = 0}	
19. Name of pharmacy {[s1f1q16_1] text} {Branching logic (show if): [refill(1)] = 0}	_____
Address of pharmacy and phone number {Branching logic (show if): [refill(1)] = 0}	
a. Number and street {[s1f1q16a_1] text} {Branching logic (show if): [refill(1)] = 0}	_____
b. City {[s1f1q16b_1] text} {Branching logic (show if): [refill(1)] = 0}	_____
c. State {[s1f1q16c_1] text} {Branching logic (show if): [refill(1)] = 0}	_____
d. Zip Code {[s1f1q16d_1] text zipcode} {Branching logic (show if): [refill(1)] = 0}	_____
e. Phone number of pharmacy {[s1f1q16e_1] text} {Branching logic (show if): [refill(1)] = 0}	_____
20. Date prescription picked up {[s1f1q17_1] text date_mdy} {Branching logic (show if): [refill(1)] = 0}	_____
21. Number of days' supply {[s1f1q18_1] text integer} {Branching logic (show if): [refill(1)] = 0}	_____
22. Name of prescribing provider {[s1f1q19_1] text} {Branching logic (show if): [refill(1)] = 0}	_____
Hydroxyurea refill 2 {Branching logic (show if): [s1f1q16_1] ""}	

19. Name of pharmacy
{[s1f1q16_2] text}
{Branching logic (show if): [s1f1q16_1] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_1] ""}

a. Number and street
{[s1f1q16a_2] text}
{Branching logic (show if): [s1f1q16_1] ""}
_____

b. City
{[s1f1q16b_2] text}
{Branching logic (show if): [s1f1q16_1] ""}
_____

c. State
{[s1f1q16c_2] text}
{Branching logic (show if): [s1f1q16_1] ""}
_____

d. Zip Code
{[s1f1q16d_2] text zipcode}
{Branching logic (show if): [s1f1q16_1] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_2] text phone}
{Branching logic (show if): [s1f1q16_1] ""}
_____

20. Date prescription picked up
{[s1f1q17_2] text date_mdy}
{Branching logic (show if): [s1f1q16_1] ""}
_____

21. Number of days' supply
{[s1f1q18_2] text integer}
{Branching logic (show if): [s1f1q16_1] ""}
_____

22. Name of prescribing provider
{[s1f1q19_2] text}
{Branching logic (show if): [s1f1q16_1] ""}
_____

Hydroxyurea refill 3
{Branching logic (show if): [s1f1q16_2] ""}

19. Name of pharmacy
{[s1f1q16_3] text}
{Branching logic (show if): [s1f1q16_2] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_2] ""}

a. Number and street
{[s1f1q16a_3] text}
{Branching logic (show if): [s1f1q16_2] ""}
_____

b. City
{[s1f1q16b_3] text}
{Branching logic (show if): [s1f1q16_2] ""}
_____

c. State
{[s1f1q16c_3] text}
{Branching logic (show if): [s1f1q16_2] ""}
_____

d. Zip Code
{[s1f1q16d_3] text zipcode}
{Branching logic (show if): [s1f1q16_2] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_3] text phone}
{Branching logic (show if): [s1f1q16_2] ""}
_____

20. Date prescription picked up
{[s1f1q17_3] text date_mdy}
{Branching logic (show if): [s1f1q16_2] ""}
_____

21. Number of days' supply
{[s1f1q18_3] text integer}
{Branching logic (show if): [s1f1q16_2] ""}
_____

22. Name of prescribing provider
{[s1f1q19_3] text}
{Branching logic (show if): [s1f1q16_2] ""}
_____

Hydroxyurea refill 4
{Branching logic (show if): [s1f1q16_3] ""}

19. Name of pharmacy
{[s1f1q16_4] text}
{Branching logic (show if): [s1f1q16_3] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_3] ""}

a. Number and street
{[s1f1q16a_4] text}
{Branching logic (show if): [s1f1q16_3] ""}
_____

b. City
{[s1f1q16b_4] text}
{Branching logic (show if): [s1f1q16_3] ""}
_____

c. State
{[s1f1q16c_4] text}
{Branching logic (show if): [s1f1q16_3] ""}
_____

d. Zip Code
{[s1f1q16d_4] text zipcode}
{Branching logic (show if): [s1f1q16_3] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_4] text phone}
{Branching logic (show if): [s1f1q16_3] ""}
_____

20. Date prescription picked up
{[s1f1q17_4] text date_mdy}
{Branching logic (show if): [s1f1q16_3] ""}
_____

21. Number of days' supply
{[s1f1q18_4] text integer}
{Branching logic (show if): [s1f1q16_3] ""}
_____

22. Name of prescribing provider
{[s1f1q19_4] text}
{Branching logic (show if): [s1f1q16_3] ""}
_____

Hydroxyurea refill 5
{Branching logic (show if): [s1f1q16_4] ""}

19. Name of pharmacy
{[s1f1q16_5] text}
{Branching logic (show if): [s1f1q16_4] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_4] ""}

a. Number and street
{[s1f1q16a_5] text}
{Branching logic (show if): [s1f1q16_4] ""}
_____

b. City
{[s1f1q16b_5] text}
{Branching logic (show if): [s1f1q16_4] ""}
_____

c. State
{[s1f1q16c_5] text}
{Branching logic (show if): [s1f1q16_4] ""}
_____

d. Zip Code
{[s1f1q16d_5] text zipcode}
{Branching logic (show if): [s1f1q16_4] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_5] text phone}
{Branching logic (show if): [s1f1q16_4] ""}
_____

20. Date prescription picked up
{[s1f1q17_5] text date_mdy}
{Branching logic (show if): [s1f1q16_4] ""}
_____

21. Number of days' supply
{[s1f1q18_5] text integer}
{Branching logic (show if): [s1f1q16_4] ""}
_____

22. Name of prescribing provider
{[s1f1q19_5] text}
{Branching logic (show if): [s1f1q16_4] ""}
_____

Hydroxyurea refill 6
{Branching logic (show if): [s1f1q16_5] ""}

19. Name of pharmacy
{[s1f1q16_6] text}
{Branching logic (show if): [s1f1q16_5] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_5] ""}

a. Number and street
{[s1f1q16a_6] text}
{Branching logic (show if): [s1f1q16_5] ""} _____

b. City
{[s1f1q16b_6] text}
{Branching logic (show if): [s1f1q16_5] ""} _____

c. State
{[s1f1q16c_6] text}
{Branching logic (show if): [s1f1q16_5] ""} _____

d. Zip Code
{[s1f1q16d_6] text zipcode}
{Branching logic (show if): [s1f1q16_5] ""} _____

e. Phone number of pharmacy
{[s1f1q16e_6] text phone}
{Branching logic (show if): [s1f1q16_5] ""} _____

20. Date prescription picked up
{[s1f1q17_6] text date_mdy}
{Branching logic (show if): [s1f1q16_5] ""} _____

21. Number of days' supply
{[s1f1q18_6] text integer}
{Branching logic (show if): [s1f1q16_5] ""} _____

22. Name of prescribing provider
{[s1f1q19_6] text}
{Branching logic (show if): [s1f1q16_5] ""} _____

Hydroxyurea refill 7
{Branching logic (show if): [s1f1q16_6] ""}

19. Name of pharmacy
{[s1f1q16_7] text}
{Branching logic (show if): [s1f1q16_6] ""} _____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_6] ""}

a. Number and street
{[s1f1q16a_7] text}
{Branching logic (show if): [s1f1q16_6] ""} _____

b. City
{[s1f1q16b_7] text}
{Branching logic (show if): [s1f1q16_6] ""} _____

c. State
{[s1f1q16c_7] text}
{Branching logic (show if): [s1f1q16_6] ""} _____

d. Zip Code
{[s1f1q16d_7] text zipcode}
{Branching logic (show if): [s1f1q16_6] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_7] text phone}
{Branching logic (show if): [s1f1q16_6] ""}
_____

20. Date prescription picked up
{[s1f1q17_7] text date_mdy}
{Branching logic (show if): [s1f1q16_6] ""}
_____

21. Number of days' supply
{[s1f1q18_7] text integer}
{Branching logic (show if): [s1f1q16_6] ""}
_____

22. Name of prescribing provider
{[s1f1q19_7] text}
{Branching logic (show if): [s1f1q16_6] ""}
_____

Hydroxyurea refill 8
{Branching logic (show if): [s1f1q16_7] ""}

19. Name of pharmacy
{[s1f1q16_8] text}
{Branching logic (show if): [s1f1q16_7] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_7] ""}

a. Number and street
{[s1f1q16a_8] text}
{Branching logic (show if): [s1f1q16_7] ""}
_____

b. City
{[s1f1q16b_8] text}
{Branching logic (show if): [s1f1q16_7] ""}
_____

c. State
{[s1f1q16c_8] text}
{Branching logic (show if): [s1f1q16_7] ""}
_____

d. Zip Code
{[s1f1q16d_8] text zipcode}
{Branching logic (show if): [s1f1q16_7] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_8] text phone}
{Branching logic (show if): [s1f1q16_7] ""}
_____

20. Date prescription picked up
{[s1f1q17_8] text date_mdy}
{Branching logic (show if): [s1f1q16_7] ""}
_____

21. Number of days' supply
{[s1f1q18_8] text integer}
{Branching logic (show if): [s1f1q16_7] ""}
_____

22. Name of prescribing provider
{[s1f1q19_8] text}
{Branching logic (show if): [s1f1q16_7] ""}
_____

Hydroxyurea refill 9
{Branching logic (show if): [s1f1q16_8] ""}

19. Name of pharmacy
{[s1f1q16_9] text}
{Branching logic (show if): [s1f1q16_8] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_8] ""}

a. Number and street
{[s1f1q16a_9] text}
{Branching logic (show if): [s1f1q16_8] ""}
_____

b. City
{[s1f1q16b_9] text}
{Branching logic (show if): [s1f1q16_8] ""}
_____

c. State
{[s1f1q16c_9] text}
{Branching logic (show if): [s1f1q16_8] ""}
_____

d. Zip Code
{[s1f1q16d_9] text zipcode}
{Branching logic (show if): [s1f1q16_8] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_9] text phone}
{Branching logic (show if): [s1f1q16_8] ""}
_____

20. Date prescription picked up
{[s1f1q17_9] text date_mdy}
{Branching logic (show if): [s1f1q16_8] ""}
_____

21. Number of days' supply
{[s1f1q18_9] text integer}
{Branching logic (show if): [s1f1q16_8] ""}
_____

22. Name of prescribing provider
{[s1f1q19_9] text}
{Branching logic (show if): [s1f1q16_8] ""}
_____

Hydroxyurea refill 10
{Branching logic (show if): [s1f1q16_9] ""}

19. Name of pharmacy
{[s1f1q16_10] text}
{Branching logic (show if): [s1f1q16_9] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_9] ""}

a. Number and street
{[s1f1q16a_10] text}
{Branching logic (show if): [s1f1q16_9] ""}
_____

b. City
{[s1f1q16b_10] text}
{Branching logic (show if): [s1f1q16_9] ""}
_____

c. State
{[s1f1q16c_10] text}
{Branching logic (show if): [s1f1q16_9] ""}
_____

d. Zip Code
{[s1f1q16d_10] text zipcode}
{Branching logic (show if): [s1f1q16_9] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_10] text phone}
{Branching logic (show if): [s1f1q16_9] ""}
_____

20. Date prescription picked up
{[s1f1q17_10] text date_mdy}
{Branching logic (show if): [s1f1q16_9] ""}
_____

21. Number of days' supply
{[s1f1q18_10] text integer}
{Branching logic (show if): [s1f1q16_9] ""}
_____

22. Name of prescribing provider
{[s1f1q19_10] text}
{Branching logic (show if): [s1f1q16_9] ""}
_____

Hydroxyurea refill 11
{Branching logic (show if): [s1f1q16_10] ""}

19. Name of pharmacy
{[s1f1q16_11] text}
{Branching logic (show if): [s1f1q16_10] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_10] ""}

a. Number and street
{[s1f1q16a_11] text}
{Branching logic (show if): [s1f1q16_10] ""}
_____

b. City
{[s1f1q16b_11] text}
{Branching logic (show if): [s1f1q16_10] ""}
_____

c. State
{[s1f1q16c_11] text}
{Branching logic (show if): [s1f1q16_10] ""}
_____

d. Zip Code
{[s1f1q16d_11] text zipcode}
{Branching logic (show if): [s1f1q16_10] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_11] text phone}
{Branching logic (show if): [s1f1q16_10] ""}

20. Date prescription picked up
{[s1f1q17_11] text date_mdy}
{Branching logic (show if): [s1f1q16_10] ""}

21. Number of days' supply
{[s1f1q18_11] text integer}
{Branching logic (show if): [s1f1q16_10] ""}

22. Name of prescribing provider
{[s1f1q19_11] text}
{Branching logic (show if): [s1f1q16_10] ""}

Hydroxyurea refill 12
{Branching logic (show if): [s1f1q16_11] ""}

19. Name of pharmacy
{[s1f1q16_12] text}
{Branching logic (show if): [s1f1q16_11] ""}

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_11] ""}

a. Number and street
{[s1f1q16a_12] text}
{Branching logic (show if): [s1f1q16_11] ""}

b. City
{[s1f1q16b_12] text}
{Branching logic (show if): [s1f1q16_11] ""}

c. State
{[s1f1q16c_12] text}
{Branching logic (show if): [s1f1q16_11] ""}

d. Zip Code
{[s1f1q16d_12] text zipcode}
{Branching logic (show if): [s1f1q16_11] ""}

e. Phone number of pharmacy
{[s1f1q16e_12] text phone}
{Branching logic (show if): [s1f1q16_11] ""}

20. Date prescription picked up
{[s1f1q17_12] text date_mdy}
{Branching logic (show if): [s1f1q16_11] ""}

21. Number of days' supply
{[s1f1q18_12] text integer}
{Branching logic (show if): [s1f1q16_11] ""}

22. Name of prescribing provider
{[s1f1q19_12] text}
{Branching logic (show if): [s1f1q16_11] ""}

Hydroxyurea refill 13
{Branching logic (show if): [s1f1q16_12] ""}

19. Name of pharmacy
{[s1f1q16_13] text}
{Branching logic (show if): [s1f1q16_12] ""}

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_12] ""}

a. Number and street
{[s1f1q16a_13] text}
{Branching logic (show if): [s1f1q16_12] ""}

b. City
{[s1f1q16b_13] text}
{Branching logic (show if): [s1f1q16_12] ""}

c. State
{[s1f1q16c_13] text}
{Branching logic (show if): [s1f1q16_12] ""}

d. Zip Code
{[s1f1q16d_13] text zipcode}
{Branching logic (show if): [s1f1q16_12] ""}

e. Phone number of pharmacy
{[s1f1q16e_13] text phone}
{Branching logic (show if): [s1f1q16_12] ""}

20. Date prescription picked up
{[s1f1q17_13] text date_mdy}
{Branching logic (show if): [s1f1q16_12] ""}

21. Number of days' supply
{[s1f1q18_13] text integer}
{Branching logic (show if): [s1f1q16_12] ""}

22. Name of prescribing provider
{[s1f1q19_13] text}
{Branching logic (show if): [s1f1q16_12] ""}

Hydroxyurea refill 14
{Branching logic (show if): [s1f1q16_13] ""}

19. Name of pharmacy
{[s1f1q16_14] text}
{Branching logic (show if): [s1f1q16_13] ""}

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_13] ""}

a. Number and street
{[s1f1q16a_14] text}
{Branching logic (show if): [s1f1q16_13] ""}

b. City
{[s1f1q16b_14] text}
{Branching logic (show if): [s1f1q16_13] ""}
_____

c. State
{[s1f1q16c_14] text}
{Branching logic (show if): [s1f1q16_13] ""}
_____

d. Zip Code
{[s1f1q16d_14] text zipcode}
{Branching logic (show if): [s1f1q16_13] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_14] text phone}
{Branching logic (show if): [s1f1q16_13] ""}
_____

20. Date prescription picked up
{[s1f1q17_14] text date_mdy}
{Branching logic (show if): [s1f1q16_13] ""}
_____

21. Number of days' supply
{[s1f1q18_14] text integer}
{Branching logic (show if): [s1f1q16_13] ""}
_____

22. Name of prescribing provider
{[s1f1q19_14] text}
{Branching logic (show if): [s1f1q16_13] ""}
_____

Hydroxyurea refill 15
{Branching logic (show if): [s1f1q16_14] ""}

19. Name of pharmacy
{[s1f1q16_15] text}
{Branching logic (show if): [s1f1q16_14] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_14] ""}

a. Number and street
{[s1f1q16a_15] text}
{Branching logic (show if): [s1f1q16_14] ""}
_____

b. City
{[s1f1q16b_15] text}
{Branching logic (show if): [s1f1q16_14] ""}
_____

c. State
{[s1f1q16c_15] text}
{Branching logic (show if): [s1f1q16_14] ""}
_____

d. Zip Code
{[s1f1q16d_15] text zipcode}
{Branching logic (show if): [s1f1q16_14] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_15] text phone}
{Branching logic (show if): [s1f1q16_14] ""}
_____

20. Date prescription picked up
{[s1f1q17_15] text date_mdy}
{Branching logic (show if): [s1f1q16_14] ""} _____

21. Number of days' supply
{[s1f1q18_15] text integer}
{Branching logic (show if): [s1f1q16_14] ""} _____

22. Name of prescribing provider
{[s1f1q19_15] text}
{Branching logic (show if): [s1f1q16_14] ""} _____

Hydroxyurea refill 16
{Branching logic (show if): [s1f1q16_15] ""}

19. Name of pharmacy
{[s1f1q16_16] text}
{Branching logic (show if): [s1f1q16_15] ""} _____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_15] ""}

a. Number and street
{[s1f1q16a_16] text}
{Branching logic (show if): [s1f1q16_15] ""} _____

b. City
{[s1f1q16b_16] text}
{Branching logic (show if): [s1f1q16_15] ""} _____

c. State
{[s1f1q16c_16] text}
{Branching logic (show if): [s1f1q16_15] ""} _____

d. Zip Code
{[s1f1q16d_16] text zipcode}
{Branching logic (show if): [s1f1q16_15] ""} _____

e. Phone number of pharmacy
{[s1f1q16e_16] text phone}
{Branching logic (show if): [s1f1q16_15] ""} _____

20. Date prescription picked up
{[s1f1q17_16] text date_mdy}
{Branching logic (show if): [s1f1q16_15] ""} _____

21. Number of days' supply
{[s1f1q18_16] text integer}
{Branching logic (show if): [s1f1q16_15] ""} _____

22. Name of prescribing provider
{[s1f1q19_16] text}
{Branching logic (show if): [s1f1q16_15] ""} _____

Hydroxyurea refill 17
{Branching logic (show if): [s1f1q16_16] ""}

19. Name of pharmacy
{[s1f1q16_17] text}
{Branching logic (show if): [s1f1q16_16] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_16] ""}

a. Number and street
{[s1f1q16a_17] text}
{Branching logic (show if): [s1f1q16_16] ""}
_____

b. City
{[s1f1q16b_17] text}
{Branching logic (show if): [s1f1q16_16] ""}
_____

c. State
{[s1f1q16c_17] text}
{Branching logic (show if): [s1f1q16_16] ""}
_____

d. Zip Code
{[s1f1q16d_17] text zipcode}
{Branching logic (show if): [s1f1q16_16] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_17] text phone}
{Branching logic (show if): [s1f1q16_16] ""}
_____

20. Date prescription picked up
{[s1f1q17_17] text date_mdy}
{Branching logic (show if): [s1f1q16_16] ""}
_____

21. Number of days' supply
{[s1f1q18_17] text integer}
{Branching logic (show if): [s1f1q16_16] ""}
_____

22. Name of prescribing provider
{[s1f1q19_17] text}
{Branching logic (show if): [s1f1q16_16] ""}
_____

Hydroxyurea refill 18
{Branching logic (show if): [s1f1q16_17] ""}

19. Name of pharmacy
{[s1f1q16_18] text}
{Branching logic (show if): [s1f1q16_17] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_17] ""}

a. Number and street
{[s1f1q16a_18] text}
{Branching logic (show if): [s1f1q16_17] ""}
_____

b. City
{[s1f1q16b_18] text}
{Branching logic (show if): [s1f1q16_17] ""}
_____

c. State
{[s1f1q16c_18] text}
{Branching logic (show if): [s1f1q16_17] ""}
_____

d. Zip Code
{[s1f1q16d_18] text zipcode}
{Branching logic (show if): [s1f1q16_17] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_18] text phone}
{Branching logic (show if): [s1f1q16_17] ""}
_____

20. Date prescription picked up
{[s1f1q17_18] text date_mdy}
{Branching logic (show if): [s1f1q16_17] ""}
_____

21. Number of days' supply
{[s1f1q18_18] text integer}
{Branching logic (show if): [s1f1q16_17] ""}
_____

22. Name of prescribing provider
{[s1f1q19_18] text}
{Branching logic (show if): [s1f1q16_17] ""}
_____

Hydroxyurea refill 19
{Branching logic (show if): [s1f1q16_18] ""}

19. Name of pharmacy
{[s1f1q16_19] text}
{Branching logic (show if): [s1f1q16_18] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_18] ""}

a. Number and street
{[s1f1q16a_19] text}
{Branching logic (show if): [s1f1q16_18] ""}
_____

b. City
{[s1f1q16b_19] text}
{Branching logic (show if): [s1f1q16_18] ""}
_____

c. State
{[s1f1q16c_19] text}
{Branching logic (show if): [s1f1q16_18] ""}
_____

d. Zip Code
{[s1f1q16d_19] text zipcode}
{Branching logic (show if): [s1f1q16_18] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_19] text phone}
{Branching logic (show if): [s1f1q16_18] ""}
_____

20. Date prescription picked up
{[s1f1q17_19] text date_mdy}
{Branching logic (show if): [s1f1q16_18] ""}
_____

21. Number of days' supply
{[s1f1q18_19] text integer}
{Branching logic (show if): [s1f1q16_18] ""}
_____

22. Name of prescribing provider
{[s1f1q19_19] text}
{Branching logic (show if): [s1f1q16_18] ""}
_____

Hydroxyurea refill 20
{Branching logic (show if): [s1f1q16_19] ""}

19. Name of pharmacy
{[s1f1q16_20] text}
{Branching logic (show if): [s1f1q16_19] ""}
_____

Address of pharmacy and phone number
{Branching logic (show if): [s1f1q16_19] ""}

a. Number and street
{[s1f1q16a_20] text}
{Branching logic (show if): [s1f1q16_19] ""}
_____

b. City
{[s1f1q16b_20] text}
{Branching logic (show if): [s1f1q16_19] ""}
_____

c. State
{[s1f1q16c_20] text}
{Branching logic (show if): [s1f1q16_19] ""}
_____

d. Zip Code
{[s1f1q16d_20] text zipcode}
{Branching logic (show if): [s1f1q16_19] ""}
_____

e. Phone number of pharmacy
{[s1f1q16e_20] text phone}
{Branching logic (show if): [s1f1q16_19] ""}
_____

20. Date prescription picked up
{[s1f1q17_20] text date_mdy}
{Branching logic (show if): [s1f1q16_19] ""}
_____

21. Number of days' supply
{[s1f1q18_20] text integer}
{Branching logic (show if): [s1f1q16_19] ""}
_____

22. Name of prescribing provider
{[s1f1q19_20] text}
{Branching logic (show if): [s1f1q16_19] ""}
_____

These are all the hydroxyurea refills available in the record up to 12 months from enrollment
{[s1f1q20a] yesno}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}

◯ Yes
◯ No

These are all the hydroxyurea refills available in the record since the previous study visit.
{[s1f1q20b] yesno}
{Branching logic (show if): [event-name] != 'baseline_arm_1'}

◯ Yes
◯ No

Patient Laboratory Reporting Form

Abstractor:
{[s1f2q00] text} _____

1. White Blood Cells
{[s1f2q01] checkbox} ☐ {1} Not available

a. Units (10^3/mm^3)
{[s1f2q01a] text number_1dp}
{Branching logic (show if): [s1f2q01(1)] = 0} _____

b. Date of most recent
{[s1f2q01b] text date_mdy}
{Branching logic (show if): [s1f2q01(1)] = 0} _____

2. Hemoglobin
{[s1f2q02] checkbox} ☐ {1} Not available

a. Units (g/dL)
{[s1f2q02a] text number_1dp}
{Branching logic (show if): [s1f2q02(1)] = 0} _____

b. Date of most recent
{[s1f2q02b] text date_mdy}
{Branching logic (show if): [s1f2q02(1)] = 0} _____

3. Hematocrit
{[s1f2q03] checkbox} ☐ {1} Not available

a. Units (%)
{[s1f2q03a] text number_1dp}
{Branching logic (show if): [s1f2q03(1)] = 0} _____

b. Date of most recent
{[s1f2q03b] text date_mdy}
{Branching logic (show if): [s1f2q03(1)] = 0} _____

4. MCV
{[s1f2q04] checkbox} ☐ {1} Not available

a. Units (fL)
{[s1f2q04a] text number_1dp}
{Branching logic (show if): [s1f2q04(1)] = 0} _____

b. Date of most recent
{[s1f2q04b] text date_mdy}
{Branching logic (show if): [s1f2q04(1)] = 0} _____

5. Platelets
{[s1f2q05] checkbox} ☐ {1} Not available

a. Units (10^3/mm^3)
{[s1f2q05a] text number_1dp}
{Branching logic (show if): [s1f2q05(1)] = 0} _____

b. Date of most recent
{[s1f2q05b] text date_mdy}
{Branching logic (show if): [s1f2q05(1)] = 0}
_____

6. Neutrophils (segmented and band together) - ANC
{[s1f2q06] checkbox}
☐ {1} Not available

a. Units (%)
{[s1f2q06a] text number_1dp}
{Branching logic (show if): [s1f2q06(1)] = 0}
_____

b. Units (10^3/mm^3)
{[s1f2q06b] text number_1dp}
{Branching logic (show if): [s1f2q06(1)] = 0}
_____

c. Date of most recent
{[s1f2q06c] text date_mdy}
{Branching logic (show if): [s1f2q06(1)] = 0}
_____

7. Reticulocytes
{[s1f2q07] checkbox}
☐ {1} Not available

a. Units (%)
{[s1f2q07a] text float}
{Branching logic (show if): [s1f2q07(1)] = 0}
_____

AND/OR

b. Units (10^3/microliter)
{[s1f2q07b] text}
{Branching logic (show if): [s1f2q07(1)] = 0}
_____

c. Date of most recent
{[s1f2q07c] text date_mdy}
{Branching logic (show if): [s1f2q07(1)] = 0}
_____

8. Serum BUN
{[s1f2q08] checkbox}
☐ {1} Not available

a. Units (mg/dL)
{[s1f2q08a] text number_1dp}
{Branching logic (show if): [s1f2q08(1)] = 0}
_____

b. Date of most recent
{[s1f2q08b] text date_mdy}
{Branching logic (show if): [s1f2q08(1)] = 0}
_____

9. Serum Creatinine
{[s1f2q09] checkbox}
☐ {1} Not available

a. Units (mg/dL)
{[s1f2q09a] text number_1dp}
{Branching logic (show if): [s1f2q09(1)] = 0}
_____

b. Date of most recent
{[s1f2q09b] text date_mdy}
{Branching logic (show if): [s1f2q09(1)] = 0}
_____

10. Bilirubin serum, total
{[s1f2q10] checkbox}
☐ {1} Not available

a. Units (mg/dL)
{[s1f2q10a] text number_1dp}
{Branching logic (show if): [s1f2q10(1)] = 0}
_____

b. Date of most recent
{[s1f2q10b] text date_mdy}
{Branching logic (show if): [s1f2q10(1)] = 0}
_____

11. Bilirubin, serum, indirect
{[s1f2q11] checkbox}
☐ {1} Not available

a. Units (mg/dL)
{[s1f2q11a] text number_1dp}
{Branching logic (show if): [s1f2q11(1)] = 0}
_____

b. Date of most recent
{[s1f2q11b] text date_mdy}
{Branching logic (show if): [s1f2q11(1)] = 0}
_____

12. AST
{[s1f2q12] checkbox}
☐ {1} Not available

a. Units (U/L)
{[s1f2q12a] text number_1dp}
{Branching logic (show if): [s1f2q12(1)] = 0}
_____

b. Date of most recent
{[s1f2q12b] text date_mdy}
{Branching logic (show if): [s1f2q12(1)] = 0}
_____

13. LDH (serum)
{[s1f2q13] checkbox}
☐ {1} Not available

a. Units (U/L)
{[s1f2q13a] text number_1dp}
{Branching logic (show if): [s1f2q13(1)] = 0}
_____

b. Date of most recent
{[s1f2q13b] text date_mdy}
{Branching logic (show if): [s1f2q13(1)] = 0}
_____

14. Hemoglobin fractionation, baseline (before HU use - if known, labs done within 3 months from baseline are acceptable)
{[s1f2q14] checkbox}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}
☐ {1} Not available

a. Units (%):
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}

1. Hb A
{[s1f2q14a_1] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

2. Hb A2
{[s1f2q14a_2] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

3. Hb C
{[s1f2q14a_3] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

4. Hb D
{[s1f2q14a_4] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

5. Hb E
{[s1f2q14a_5] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

6. Hb F
{[s1f2q14a_6] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

7. Hb O
{[s1f2q14a_7] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

8. Hb S
{[s1f2q14a_8] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

9. Other
{[s1f2q14a_9] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

Other, specify:
{[s1f2q14a_9_sp] text}
{Branching logic (show if): [s1f2q14a_9] ""}
_____

b. Date of most recent
{[s1f2q14b] text date_mdy}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q14(1)] = 0}
_____

15. Most recent hemoglobin fractionation
{[s1f2q15] checkbox}
{Branching logic (show if): [event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1'}

☐ {1} Not available

a. Units (%):
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

1. Hb A
{[s1f2q15a_1] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

_____

2. Hb A2
{[s1f2q15a_2] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

_____

3. Hb C
{[s1f2q15a_3] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

_____

4. Hb D
{[s1f2q15a_4] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

_____

5. Hb E
{[s1f2q15a_5] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

_____

6. Hb F
{[s1f2q15a_6] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

_____

7. Hb O
{[s1f2q15a_7] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}

_____

8. Hb S
{[s1f2q15a_8] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}
_____

9. Other
{[s1f2q15a_9] text number_1dp}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}
_____

Other, specify:
{[s1f2q15a_9_sp] text}
{Branching logic (show if): [s1f2q15a_9] ""}
_____

b. Date of most recent
{[s1f2q15b] text date_mdy}
{Branching logic (show if): ([event-name] = '12_weeks_arm_1' or [event-name] = '24_weeks_arm_1' or [event-name] = '36_weeks_arm_1') and [s1f2q15(1)] = 0}
_____

16. Hemoglobin fractionation, maximum dose HU (historical data)
{[s1f2q16] checkbox}
{Branching logic (show if): [event-name] = 'baseline_arm_1'}
☐ {1} Not in record

a. Units (%)
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}

1. Hb A
{[s1f2q16a_1] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

2. Hb A2
{[s1f2q16a_2] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

3. Hb C
{[s1f2q16a_3] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

4. Hb D
{[s1f2q16a_4] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

5. Hb E
{[s1f2q16a_5] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

6. Hb F
{[s1f2q16a_6] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

7. Hb O
{[s1f2q16a_7] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

8. Hb S
{[s1f2q16a_8] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

9. Other
{[s1f2q16a_9] text number_1dp}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

Other, specify:
{[s1f2q16a_9_sp] text}
{Branching logic (show if): [s1f2q16a_9] ""}
_____

b. Date of most recent
{[s1f2q16b] text date_mdy}
{Branching logic (show if): [event-name] = 'baseline_arm_1' and [s1f2q16(1)] = 0}
_____

Patient Protocol Deviation Form

This form is completed for any events performed outside the study guidelines outlined in the protocol. One protocol deviation form should be completed for each and every protocol deviation.

1. Date of protocol deviation:
{[s1f4q01] text date_mdy}

_____

2. Choose the applicable visit for this protocol deviation.
{[s1f4q02] radio}

◯ {1} Pre-Baseline (-24 weeks, retrospective data collection)
◯ {2} Baseline
◯ {3} Week 12 Visit
◯ {4} Week 24 Visit (Study Exit)
◯ {5} Post Study (Weeks 25-36)

3. Type of protocol deviation:
{[s1f4q03] dropdown}

◯ {1} Visit Missed
◯ {2} Visit Out-of-Window
◯ {3} Visit/Assessment Incomplete (includes form not being complete)
◯ {4} Informed Consent
◯ {5} Eligibility
◯ {6} Study Procedure/Assessment
◯ {7} Other
(Choose one.)

3a. If 'Other', please specify:
{[s1f4q03a] text}
{Branching logic (show if): [s1f4q03] =7}

_____

4. Does the site's IRB require this deviation to be reported to them?
{[s1f4q04] yesno}

◯ Yes
◯ No

5. Circumstances of the protocol deviation (if deviation is incomplete or missed assessments/visits then state visit/assessment for which the deviation occurred):
{[s1f4q05] textarea}

_____

Patient Final Status Form

Complete this form for all subjects enrolled in the study to document the final status of each person.

1. Date of final status (last time individual completed study assessment or provided study data): {[s1f5q01] text date_mdy}	_____
2. Final Status: {[s1f5q02] radio}	◯ {1} Completed study per protocol (i.e., all study visits and study assessments were completed) ◯ {2} Ineligible (data will be destroyed) ◯ {3} Lost to follow-up ◯ {4} Withdrew from study ◯ {5} Death
2a. If 'Ineligible' or 'Withdrew from study', provide reason: {[s1f5q02a] text} {Branching logic (show if): [s1f5q02] = 2 or [s1f5q02] =4}	_____
2b. If 'Lost to follow-up', provide date determination was made to no longer attempt to contact: {[s1f5q02b] text date_mdy} {Branching logic (show if): [s1f5q02] = 3}	_____
2c. If 'Death', provide date last known alive OR date of death: {[s1f5q02c] text date_mdy} {Branching logic (show if): [s1f5q02] = 5}	_____
3. Additional Comments (if applicable): {[s1f5q03] textarea}	_____