Public Use Dataset
Annotated eCRF

Intravenous Magnesium for Sickle Cell Vasoocclusive Crisis

(Magnesium in Crisis (MAGiC))

PECARN Protocol Number 025
_____

Pediatric Emergency Care Applied Research Network

National Institute for Child Health and Human Development (NICHD)

Protocol Version 1.05

Version Date: September 7, 2012

PUD Annotated eCRF Version 1.0

Version Date: March 27, 2017

Table of Contents:

Annotations key:

Table name

Column name followed by: # or N
= numeric
N = character N = length

Format (name)
Code list

Calculated / Derived variable

Value not provided

Table name_Child table name

Variable in question group

Notes:

StudySubjectID is the original identifier. A new masked identifier named PudId has been created; this variable is present in all datasets to facilitate merging. We will retain a dataset that links the original StudySubjectID to the PudID for internal records.

After the new masked identifier is created and used to replace the original, each public use dataset is sorted by its unique identifier(s). This will ensure that the final sorting of records does not correspond to the ordering of the original identifier.

All out of range and other questionable data has been included in the public use datasets.

Sensitive and/or identifying information entered in free text fields has been modified as needed or removed from the public use datasets.

All date variables are recoded to be number of days since emergency department (ED) arrival. Variable names and labels are changed as well. For example, the variable AEStartDate will be called AEStartDay and the label will change from "Adverse Event Start Date" to "Adverse Event Start Day (relative to ED arrival)". No actual dates will be included.

Many of the datasets include only one record per subject (unique identifier *PudId*). Other datasets are relational, that is, may have more than one record per subject. These records are uniquely identified by *PudId* and *ItemGroupRepeatKey, PudId* and *Occurrence,* or a combination of *PudId, ItemGroupRepeatKey,* and *Occurrence*.

The datasets are primarily based on raw datasets (i.e., as captured in study database with minimal modifications). Selected derived data elements will also be included, namely transformed QL scores.

25 Hr Magnesium Levels: This data is only available for a subset of subjects (those enrolled prior to v1.04 of protocol). The purpose of collecting this data, originally, was to confirm that the magnesium dose administered was not an unsafe dose amount. The DSMB approved the discontinuation of the collection of these data (Protocol: v1.04+).

MAGiC Patient Eligibility:

| Inclusi...(0/7) | Exclusi...(0/20) | Eligibi...(0/15) | ▶ | -- Select to Jump -- ▾ |

Title: Inclusion Criteria

Date and Time of Emergency Department Arrival:

EDTime, $5

Date: [_____] 🔲 *   EDDay, #   Time: [_____] (HHMM)

Date Patient was Screened for Eligibility:

Screening Date: [_____] 🔲 * (DD-MMM-YYYY)   ScreenDay, #

1. Is the patient between 4 and 21 years of age, inclusive?

◯ Yes ◯ No *   Inclusion1, #

2. Does the patient have Hb SS or Hb Sβ° Thalassemia disease?

◯ Yes ◯ No *   Inclusion2, #

3. Did the patient fail intravenous opioid pain management in the ED prior to the decision to admit the patient to the hospital?

◯ Yes ◯ No *   Inclusion3, #

4. Has the decision been made to admit the patient to the inpatient unit for sickle cell pain crisis?

◯ Yes ◯ No *   Inclusion4, #

If patient does not meet inclusion criteria, do not save this information to the database.

YesNo
1 = Yes
0 = No

| Inclusi...(0/7) | Exclusi...(0/22) | Eligibi...(0/15) | ▶ | -- Select to Jump -- ▾ |

Title: Exclusion Criteria

1. Has the patient received more than 12 hours of intravenous pain medication prior to enrollment?

◯ Yes ◯ No *   Exclusion1, #

2. Has the patient had a previous enrollment in this study?

◯ Yes ◯ No *   Exclusion2, #

3. Does the patient have a history of allergy/intolerance to both intravenous morphine and hydromorphone?

◯ Yes ◯ No *   Exclusion3, #

4. Does the patient have a known other cause for current pain - (avascular necrosis, gall bladder disease, priapism, etc.)?

◯ Yes ◯ No *   Exclusion4, #

5. Has the patient had greater than 10 admissions for pain crisis in the past year?

◯ Yes ◯ No *   Exclusion5, #

6. Does the patient have pain from current crisis of greater than 5 days duration?

◯ Yes ◯ No *   Exclusion6, #

7. Is the patient maintained on daily opioids or chronic transfusions for chronic sickle cell pain?

◯ Yes ◯ No *   Exclusion7, #

8. Has the patient had a blood transfusion within the previous two months?

◯ Yes ◯ No *   Exclusion8, #

9. Does the patient have known kidney or liver failure (elevation of LFTs would not warrant exclusion)?

◯ Yes ◯ No *   Exclusion9, #

YesNo
1 = Yes
0 = No

10. Does the patient have known pulmonary hypertension?

   ○ Yes ○ No * | Exclusion10, # |

11. Is the patient known to be pregnant?

   ○ Yes ○ No * | Exclusion11, # |

12. Does the patient have a diagnosis of bacterial infection?

   ○ Yes ○ No * | Exclusion12, # |

13. Does the patient have a diagnosis of fever ≥ 39.5° C (103.1° F)?

   ○ Yes ○ No * | Exclusion13, # |

14. Does the patient have a diagnosis of acute chest syndrome?

   ○ Yes ○ No * | Exclusion14, # |

15. Does the patient have a diagnosis of hemodynamic instability?

   ○ Yes ○ No * | Exclusion15, # |

16. Does the patient have a diagnosis of sepsis?

   ○ Yes ○ No * | Exclusion16, # |

17. Is the patient currently on oral magnesium supplementation or currently enrolled in another therapeutic study protocol?

   ○ Yes ○ No * | Exclusion17, # |

18. Has the patient been previously diagnosed with a clinical stroke?

   ○ Yes ○ No * | Exclusion18, # |

20. Does the patient have current or planned use of neuromuscular blocker, nifedipine, ritodrine, or terbutaline?

   ○ Yes ○ No * | Exclusion20, # |

21. Does the patient have an allergy to magnesium sulfate?

   ○ Yes ○ No * | Exclusion21, # |

22. Has the patient been discharged from an inpatient unit within 72 hours of arrival in the ED for the current pain crisis?

   ○ Yes ○ No | Exclusion22, # |

YesNo
1 = Yes
0 = No

Title: Eligibility & Consent

Is the patient eligible?

Eligible patients have all inclusion criteria as Yes, and all exclusion criteria as No.

○ Yes ○ No *

Eligibility, #

YesNo
1 = Yes
0 = No

If "no", select "mark complete", save this page and do not continue. Data entry for this patient is complete.

Parental / Patient Consent: *(Patient = 18 years of age)*

Was the patient / parent pre-consented?

(select one) ▼

PreConsentGiven, #

YesNoS
1 = Yes
0 = No

Were the parent(s) / patient approached for consent? (If pre-consented, were the parent(s) / patient approached for confirmation of eligibility?)

(select one) ▼ If "no", provide reason why

ConsentApproach, #

YesNoS
1 = Yes
0 = No

Reason why parent(s) / patient not approached for consent?

(select one) ▼ — Value not provided

Other reason (specify):

Value not provided

If parent or patient not approached due to physician preference, please provide reason here:

Value not provided

Did the parent(s) / patient give consent?

(select one) ▼ If "yes", provide date/time

Consent, #

YesNoS
1 = Yes
0 = No

Consent Date: ConsentDay, # ▦ (DD-MMM-YYYY)   Consent Time: ConsentTime, $5 (HHMM)

If parent or patient refused participation in study and **offered** a reason why, please provide reason here:

Value not provided

AssentTm
1 = In the clinic (prior to current hospitalization)
2 = In the ED or on the floor but prior to randomization
3 = After randomization but prior to last study drug infusion
4 = After the last study drug infusion but prior to hospital discharge
5 = At the time of follow-up

Child Assent:

Was the child approached for assent?

(select one) ▼

AssentApproach, #

YesNoS
1 = Yes
0 = No

If yes, at what time point was the child approached for assent?

(select one) ▼

AssentTimeApproach, #

Did the child give assent?

YesNoS
1 = Yes
0 = No

Assent, # (select one) ▼ If "yes", provide date/time

Assent Date: AssentDay, # ▦ (DD-MMM-YYYY)   Assent Time: AssentTime, $5 (HHMM)

LaterIneligible, #

YesNo
1 = Yes
0 = No

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MAGiC Patient Demographics:

Demog (0/4) ► -- Select to Jump --

Title: Patient Demographics

Date of birth: [Age, #] 🔲 * (DD-MMM-YYYY)

Sex: ○ Male ○ Female * [Sex, #]

Sex
1 = Male
2 = Female

Ethnicity: ○ Hispanic or Latino *
○ Not Hispanic or Latino
○ Unknown or Not Reported

Race: ☐ American Indian or Alaska Native *
(select all that apply) ☐ Asian
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Unknown or Not Reported

[Ethnicity, #]

Ethnic
1 = Hispanic or Latino
2 = Not Hispanic or Latino
92 = Unknown or Not Reported

[NIHRace, #]

NIHRace
1 = American Indian or Alaska Native
2 = Asian
3 = Black or African American
4 = Native Hawaiian or Other Pacific Islander
5 = White
6 = Multi-race
92 = Unknown or Not Reported

MAGiC Patient Randomization:

◄ **Randomi...(0/8)** ► -- Select to Jump -- ▼

Title: Patient Randomization

Was patient randomized into the study?

○ Yes * If "yes," please complete the rest of this form.
○ No   If "no," please provide reason why.

PtRandomized, #

YesNo
1 = Yes
0 = No

Reason why patient was not randomized:

(select one) — NotRandReason, # ▼

Other reason (specify): — NotRandReasonOther, $108

Please select the patient's age group:

(select one) ▼ — StratifyAge, #

Strat
1 = 4 to 11 years of age
2 = 12 to 21 years of age

Has the patient been treated with hydroxyurea within 3 months prior to randomization?

(select one) ▼ — HydroxyureaUse, #

YesNoS
1 = Yes
0 = No

Randomization Date: RandDay, # 📅 (DD-MMM-YYYY)   **Randomization Time:** RandTime, $5 (HH:MM)

Randomization Number: Value not provided

NoRand
1 = Patient had received IV opioid medication for greater than 12 hours before randomization could be accomplished
2 = Patient developed other exclusion criteria before randomization could be accomplished
3 = Withdrawal of consent prior to randomization
90 = Other reason (specify)

Variable	Format	Type	Label	Algorithm / Notes
AssignedTreatmentGroup	TrtFmt	#	Which treatment was the patient assigned to?	
ReceivedTreatmentGroup	TrtFmt	#	Which treatment did the patient receive?	
RandomizationAge		#	Age (in years) at Randomization	
ITT	YesNo	#	Is the patient in the ITT Population?	
PerProtocol	YesNo	#	Is the patient in the Per Protocol population?	
SafetyPopulation	YesNo	#	Is the patient in the safety population?	
Strata		$2	Treatment Strata	

TrtFmt
1 = Placebo
0 = Magnesium

YesNo
1 = Yes
0 = No

MAGiC Previous Medical History & History of Illness:

Title: Illness History

Illness...(0/4) | Clinic ...(0/7) | PMH1 (0/18) | -- Select to Jump --

Illness History:

Does the patient have a history of:

Acute Chest Syndrome: ○ Yes ○ No ○ Unknown *

HistoryACS, #

Asthma: ○ Yes ○ No ○ Unknown *

HistoryAsthma, #

YesNoUk
1 = Yes
0 = No
92 = Unknown

Was the patient hospitalized for a pain crisis in the past 3 years?

YesNo
1 = Yes
0 = No

HistoryPainCrisis, #

○ Yes ○ No *

If yes, how many times in the past 3 years:

PainCrisisVisits, #

Illness...(0/4) | Clinic ...(0/5) | PMH1 (0/14) | -- Select to Jump --

Title: Clinic Visit Information

Instructions: Please record patient's blood pressure from most recent clinic visit (within past 12 months) when patient was well.
If the clinic visit information is not available, please provide the 50% percentile information.

Most Recent WELL Clinic Visit Information:

Is there a blood pressure available from a well clinic visit within the past 12 months?

YesNoS
1 = Yes
0 = No

ClinicVisit, #

...ne) ▼ * If no, please record 50th percentile information.

Date of Visit when BP was taken:

ClinicDay, #

(DD-MMM-YYYY)

Clinic Systolic BP:

ClinicSBP, #

(mm/Hg)

50th Percentile Systolic Blood Pressure Information:

Only complete this section if well clinic visit information is not available.
To determine the 50% SBP, please consult the 'Median Age and Height Chart' provided by the CDMCC.

Height: (cm)

MedianHeight, #

50th percentile Systolic BP:

MedianSBP, #

(mm/Hg)

| ◄ | Clinic ...(0/7) | **PMH1** (0/18) | PMH2 (0/10) | ► | -- Select to Jump -- ☑ |

Title: Previous Medical History; Section One

Instructions: **Indicate Normal, Abnormal, or Unknown for every system. If abnormal, then you must provide a description.**

Date and Time of Review of Systems:

Date: MHDay, # 📅 * (DD-MMM-YYYY)   Time: MHTime, $5 * (HH:MM)

HEENT Review:

MHHEENT, #
- ○ Normal *
- ○ Abnormal
- ○ Unknown

If "Abnormal", please provide description: Value not provided

Cardiovascular Review:

MHCardio, #
- ○ Normal *
- ○ Abnormal
- ○ Unknown

If "Abnormal", please provide description: Value not provided

Respiratory or Pulmonary Review:

MHRespPulm, #
- ○ Normal *
- ○ Abnormal
- ○ Unknown

If "Abnormal", please provide description: Value not provided

Gastrointestinal Review:

MHGI, #
- ○ Normal *
- ○ Abnormal
- ○ Unknown

If "Abnormal", please provide description: Value not provided

NormAbUk
1 = Normal
2 = Abnormal
92 = Unknown

Hepatic Review:

MHHepatic, #
- ○ Normal *
- ○ Abnormal
- ○ Unknown

If "Abnormal", please provide description: Value not provided

Genitourinary Review:

MHGenitourine, #
- ○ Normal *
- ○ Abnormal
- ○ Unknown

If "Abnormal", please provide description: Value not provided

◄ | Clinic ...(0/5) | PMH1 (0/14) | **PMH2** (0/14) | ► | -- Select to Jump -- ▼

Title: Previous Medical History; Section Two

Instructions: Indicate Normal, Abnormal, or Unknown for every system. If abnormal, then you must provide a description.

Renal Review:

MHRenal, #

○ Normal *
○ Abnormal
○ Unknown

If "Abnormal", please provide description:

Value not provided

Neurologic Review:

MHNeuro, #

○ Normal *
○ Abnormal
○ Unknown

If "Abnormal", please provide description:

Value not provided

Psychiatric / Behavioral Review:

MHPsych, #

○ Normal *
○ Abnormal
○ Unknown

If "Abnormal", please provide description:

Value not provided

NormAbUk
1 = Normal
2 = Abnormal
92 = Unknown

Endocrine Review:

MHEndo, #

○ Normal *
○ Abnormal
○ Unknown

If "Abnormal", please provide description:

Value not provided

Hematologic Review:

MHHeme, #

○ Normal *
○ Abnormal
○ Unknown

If "Abnormal", please provide description:

Value not provided

Musculoskeletal Review:

MHMusculo, #

○ Normal *
○ Abnormal
○ Unknown

If "Abnormal", please provide description:

Value not provided

Dermatologic Review:

MHDerm, #

○ Normal *
○ Abnormal
○ Unknown

If "Abnormal", please provide description:

Value not provided

MAGiC Baseline Information:

Baselin...(0/2) | Baselin...(0/8) | Baselin...(0/20) | ▶ | -- Select to Jump -- ▼

Title: Baseline Information:

Date and Time of Admission to Hospital: AdmitDay, #   AdmitTime, $5

Date: [_____] 📅 * (DD-MMM-YYYY)   Time: [_____] (HHMM)

Baselin...(0/4) | Baselin...(0/8) | Baselin...(0/20) | ▶ | -- Select to Jump -- ▼

Title: Baseline Vital Measurements:

Instructions: All vitals in this section MUST be obtained upon patient's arrival to the ED or at triage.

Date: VSDay, # 📅 (DD-MMM-YYYY)   Time: VSTime, $5 (HH:MM)

Temperature: Temperature, # (°C/°F)   Respiratory Rate: RespRate, # (breaths/min)   Heart Rate: HeartRate, # (bpm)

Systolic BP: SBP, # (mm/Hg)   Diastolic BP: DBP, # (mm/Hg)   O2Sat: PulseOx, # (%)

Baselin...(0/8) | Baselin...(0/20) | Prior t...(0/8) | ▶ | -- Select to Jump -- ▼

Title: Baseline Labs:

Instructions: All labs in this section MUST be obtained PRIOR to receiving first study drug infusion.

Hematology Labs: Baseline_BaseHemLabs

Date:	Time: (HH:MM)	Hematocrit: (%)	Hgb: (g/100mL)	WBC: (x 10^3/uL)	Platelets: (x 10^3/uL)	Reticulocytes: (%)	
HemLabDay, #	HemLabTime, $5	Hematocrit, #	Hemoglobin, #	WBC, #	Platelets, #	Reticulocytes, #	X

ADD

Electrolyte Labs: Baseline_BaseElecLabs

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Sodium: (mEq/L)	Potassium: (mEq/L)	Chloride: (mEq/L)	Bicarbonate: (mEq/L)	BUN: (mg/dL)	Creatinine: (mg/dL)	
ElecLabDay, #	ElecLabTime, $5	Sodium, #	Potassium, #	Chloride, #	Bicarb, #	BUN, #	Creatinine, #	X

ADD

Chemistry Labs: Baseline_BaseChemLabs

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Calcium: (mg/dL)	Magnesium: (mg/dL)	Lactate dehydrogenase: (IU/L)	
ChemLabDay, #	ChemLabTime, $5	Calcium, #	Magnesium, #	LDH, #	X

ADD

Baselin...(0/20) | **Prior t...(0/12)** | ED Non-...(0/4) | ► | -- Select to Jump -- ▼

Title: Medications Taken Prior to ED Arrival:

Instructions: **Please record all medications taken in the *12 hours* prior to arrival at the ED.**

Did the patient take non-opioid medications in the 12 hours prior to arrival at the Emergency Department?

OPNonOpioidTaken, #

YesNo
1 = Yes
0 = No

(select one) ▼ *

Non-Opioid Medications Prior to ED:

Baseline_OPNonOpioid

Non-opioid medication name:	Date: (DD-MMM-YYYY)	Time: (HHMM)
CodedOPNonOpioidName, $255	OPNonOpioidDay, #	OPNonOpioidTime, $5
NonCodedOPNonOpioidName, $29		

Did the patient take opioid medications in the 12 hours prior to arrival at the Emergency Department?

OPOpioidTaken, #

YesNo
1 = Yes
0 = No

(select one) ▼ *

Opioid Medications Prior to ED:

OPOpioidDose, #

Opioid medication name:	Other name of opioid (specify):	Date: (DD-MMM-YYYY)	Time: (HHMM)	Total Dose:	Dose Unit:	Other dose unit (specify):	
OPOpioidName, #	OPOpioidNameOther, $255	OPOpioidDay, #	OPOpioidTime, $5		(select one) ▼	OPOpioidDoseUnitOther, $4	

ADD

OPOpioidDoseUnit, #

Baseline_OPOpioid

DoseUnit
1 = mg
2 = mcg
90 = other

◄ Prior t...(0/12) | **ED Non-...(0/4)** | ED Opio...(0/11) | ► | -- Select to Jump -- ▼

Title: Non-Opioid Medications Taken After ED Arrival But Prior to Randomization:

Instructions: **Please record all non-opioid medications taken by the patient *after* arrival in the ED but *prior* to randomization.**

Did the patient receive non-opioid medications while in the Emergency Department up to the time of randomization?

EDNonOpioidTaken, #

YesNo
1 = Yes
0 = No

(select one) ▼ *

Non-Opioid ED to Randomization:

Baseline_EDNonOpioid

Non-opioid medication name:	Date: (DD-MMM-YYYY)	Time: (HHMM)	
CodedEDNonOpioidName, $255	EDNonOpioidDay, #	EDNonOpioidTime, $5	X
NonCodedEDNonOpioidName, $65			

EDMedNam
1 = Morphine
2 = Morphine SR
3 = Hydromorphone
4 = Fentanyl
5 = Codeine
6 = Oxycodone
90 = Other (specify)

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Prior t...(0/12) | ED Non-...(0/4) | **ED Opio...(0/11)** | ► | -- Select to Jump --

Title: Opioid Medications Taken After ED Arrival but Prior to First Study Drug Infusion:

Instructions: Please record all opioid medications taken by the patient *after* arrival in the ED but *prior* to first study drug infusion.

Did the patient receive opioid medications while in the Emergency Department up to the time of first study drug infusion?

(select one) ▼ *   **EDOpioidTaken, #**

YesNo
1 = Yes
0 = No

Opioid ED to First Study Drug Infusion

Name of Opioid:	Other name of opioid (specify):	Date started: (DD-MMM-YYYY)	Time started: (HHMM)	Date stopped: (DD-MMM-YYYY)
EDOpioidName, #	EDOpioidNameOther, $255	EDOpioidStartDay, #	EDOpioidStartTime, $5	EDOpioidStopDay, #

ADD

EDOpioidDoseBasal, #

EDOpioidDoseUnit, #

EDOpioidRoute, #

Time stopped: (HHMM)	Total Dose Given: BASAL	Total Dose Given: DEMAND	Dose unit:	Other dose unit (specify):	Route:
EDOpioidStopTime, $5		EDOpioidDoseDemand, #	elect one)	EDOpioidDoseUnitOther, $201	elect one) ▼ X

Baseline_EDOpioid

DoseUnit
1 = mg
2 = mcg
90 = other

EDRoute
1 = Continuous IV (Including PCA)
2 = Intermittent IV Bolus
3 = Oral

EDMedNam
1 = Morphine
2 = Morphine SR
3 = Hydromorphone
4 = Fentanyl
5 = Codeine
6 = Oxycodone
90 = Other (specify)

MAGiC Physical Exam:

Physica...(0/17) | Physica...(0/15) | ▶ | -- Select to Jump --

Title: Physical Examination; Section One

Instructions: The Physical Examination *MUST* be completed immediately prior to the time of randomization.

Present Illness Information:

When did the pain start for this current sickle cell crisis?

(select one) ▼ * | OnsetPainDate, #

DateSick
1 = Today
2 = Yesterday
3 = 2 days ago
4 = 3 days ago
5 = 4 days ago
6 = 5 days ago
7 = Greater than 5 days ago

Please select the type of sickle cell disease this patient has:

DiseaseType, # | (select one) ▼ * Hb SS = Sickle Cell Anemia
Hb Sβ° = Sickle Beta-Zero

DzType
1 = Sickle Cell Anemia
2 = Sickle Beta-Zero

Physical Exam:
Indicate Normal, Abnormal, or Not assessed for every system. If abnormal, then you must provide a description.

Date and Time of Physical Examination:

Date: PEDay, # 🗓 * (DD-MMM-YYYY) | Time: PETime, $5 (HHMM)

Weight:

PEWeight, # * (kg)

HEENT Examination Findings:

PEHEENT, # | ○ Normal * | If "Abnormal", please provide description: | Value not provided
| ○ Abnormal
| ○ Not assessed

Cardiovascular Examination Findings:

PECardio, # | ○ Normal * | If "Abnormal", please provide description: | Value not provided
| ○ Abnormal
| ○ Not assessed

Respiratory or Pulmonary Examination Findings:

PERespPulm, # | ○ Normal * | If "Abnormal", please provide description: | Value not provided
| ○ Abnormal
| ○ Not assessed

NormAbAs
1 = Normal
2 = Abnormal
99 = Not assessed

Gastrointestinal Examination Findings:

PEGI, # | ○ Normal * | If "Abnormal", please provide description: | Value not provided
| ○ Abnormal
| ○ Not assessed

Hepatic Examination Findings:

PEHepatic, # | ○ Normal * | If "Abnormal", please provide description: | Value not provided
| ○ Abnormal
| ○ Not assessed

Genitourinary Examination Findings:

PEGU, # | ○ Normal * | If "Abnormal", please provide description: | Value not provided
| ○ Abnormal
| ○ Not assessed

Physica...(0/17) **Physica...(0/15)** ► -- Select to Jump -- ▼

Title: Physical Examination; Section Two

Indicate Normal, Abnormal, or Not assessed for every system. If abnormal, then you must provide a description.

Renal Examination Findings:

PERenal, #
○ Normal *
○ Abnormal
○ Not assessed

If "Abnormal", please provide description: | Value not provided

Neurologic Examination Findings:

PENeuro, #
○ Normal *
○ Abnormal
○ Not assessed

If "Abnormal", please provide description: | Value not provided

Psychiatric/Behavioral Examination Findings:

PEPsych, #
○ Normal *
○ Abnormal
○ Not assessed

If "Abnormal", please provide description: | Value not provided

Endocrine Examination Findings:

PEEndo, #
○ Normal *
○ Abnormal
○ Not assessed

If "Abnormal", please provide description: | Value not provided

NormAbAs
1 = Normal
2 = Abnormal
99 = Not assessed

Hematologic Examination Findings:

PEHeme, #
○ Normal *
○ Abnormal
○ Not assessed

If "Abnormal", please provide description: | Value not provided

Musculoskeletal Examination Findings:

PEMusculo, #
○ Normal *
○ Abnormal
○ Not assessed

If "Abnormal", please provide description: | Value not provided

Dermatologic Examination Findings:

PEDerm, #
○ Normal *
○ Abnormal
○ Not assessed

If "Abnormal", please provide description: | Value not provided

Additional Comments about the Physical Examination (optional):

Value not provided

PhysioGroup, #

PhysioG
1 = Simple crisis (no fever; no ACS)
2 = Pain with fever on arrival in ED (no ACS)
3 = Pain crisis, developed ACS at any time
4 = Did not have a pain crisis

MAGiC Daily Data Collection:

| Daily D...(0/15) | Study L...(0/22) | ▶ | -- Select to Jump -- |

Title: Daily Data Collection:

Instructions: **Study day zero is defined as the time of randomization until 23:59. All subsequent study days are calendar days. The last study day ends when the subject is discharged from the hospital or 12 hours after the last IV opioid administration, whichever comes first.**

Study Date:

DailyDay, #   * (DD-MMM-YYYY)

Did the patient report any of the following on this day:
If yes, please consult with your PI to determine if this should be reported as an AE.

Weakness? ○ Yes ○ No *   DailyWeakness, #

Dizziness? ○ Yes ○ No *   DailyDizziness, #

Did the patient experience any of the following on this day:
If yes, please consult with your PI to determine if this should be reported as an AE.

Cough? ○ Yes ○ No *   DailyCough, #

Any Other NEW Symptoms? ○ Yes ○ No *   If yes, please describe: Value not provided

DailyOtherNewSymp, #

Did patient receive any of the following on this day?

Non-study medication, excluding opioids & ketorolac? ○ Yes ○ No * If yes, record on concomitant medications log   DailyConMed, #

Opioids? ○ Yes ○ No * If yes, record on opioid log   DailyOpioid, #

Ketorolac? ○ Yes ○ No * If yes, record on the ketorolac log   DailyKetorolac, #

Blood transfusions? ○ Yes ○ No * If yes, record on blood transfusions log   DailyTrans, #

Has the patient been diagnosed with any of the following on this day:
If yes, please consult with your PI to determine if this should be reported as an AE.

Acute Chest Syndrome? ○ Yes ○ No *   DailyACS, #

Priapism? ○ Yes ○ No *   DailyPriapism, #

Stroke? ○ Yes ○ No *   DailyStroke, #

Other major organ events relating to vasoocclusion? ○ Yes ○ No *   If yes, please describe: Value not provided

DailyOtherMajorEvents, #

YesNo
1 = Yes
0 = No

Daily D...(0/17) | Study L...(0/22) | -- Select to Jump --

Title: Daily Study Labs:

Instructions: Please Note: Electrolyte and Chemistry Labs, plus Magnesium, *MUST* be drawn one hour after the initiation of the *FOURTH* study drug infusion.

Were hematology labs drawn on this study day?

○ Yes ○ No *   HemLabDrawn, #

Hematology Labs: DailyData_HemLabs

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Hematocrit: (%)	Hgb: (g/100mL)	WBC: (x 10^3/uL)	Platelets: (x 10^3/uL)	Reticulocytes: (%)
HemLabDay, #	HemLabTime, $5	Hematocrit, #	Hemoglobin, #	WBC, #	Platelets, #	Reticulocytes, #

ADD

Were electrolyte labs drawn on this study day?

○ Yes ○ No *   ElecLabDrawn, #

Electrolyte Labs: DailyData_ElecLabs

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Sodium: (mEq/L)	Potassium: (mEq/L)	Chloride: (mEq/L)	Bicarb: (mEq/L)	BUN: (mg/dL)	Creatinine: (mg/dL)
ElecLabDay, #	ElecLabTime, $5	Sodium, #	Potassium, #	Chloride, #	Bicarb, #	BUN, #	Creatinine, #

ADD

Were chemistry labs drawn on this study day?

○ Yes ○ No *   ChemLabDrawn, #

Chemistry Labs: DailyData_ChemLabs

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Calcium: (mg/dL)	Lactate dehydrogenase: (IU/L)
ChemLabDay, #	ChemLabTime, $5	Calcium, #	LDH, #

ADD

YesNo
1 = Yes
0 = No

MAGiC Study Drug Administration – 1st Infusion:

1st Inf...(0/19) ► -- Select to Jump --

Title: 1st Infusion:

Study Drug Administration:

Did the study drug administration occur?

○ Yes ○ No * If yes, please answer the remaining questions on this tab. If no, please provide a reason why.

MedAdminHappen, #

YesNo
1 = Yes
0 = No

If study drug was not administered, please provide reason why:

(select one)

WhyNoMedAdmin, #

Other (specify): Value not provided

Study Drug Infusion Information:

| Start Date: | InfusionStartDay, # | (MMM-YYYY) | Start Time: | InfusionStartTime, $5 | (M) |

| Stop Date: | InfusionStopDay, # | (MMM-YYYY) | Stop Time: | InfusionStopTime, $5 | (M) |

Total Dose: InfusionDose, # (mL)

Was infusion of the study drug slowed?

(select one) If yes, please document reason on AE and/or OOPS log

InfusionSlowed, #

Infusion Vital Measurements:

DrugAdmin1_VS1

One set of vitals MUST be obtained PRIOR to starting first study drug infusion.
Please record vitals every 10 minutes until 30 minutes after the completion of infusion.

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Heart Rate: (bpm)	Systolic BP: (mm/Hg)	Diastolic BP: (mm/Hg)	O2Sat: (%)	
VSDay, #	VSTime, $5	HeartRate, #	SBP, #	DBP, #	PulseOx, #	X

ADD

Study Drug Side Effects During THIS Infusion:

Did the patient experience any of the following:

Hypotension associated with infusion? (select one) (>20% SBP reduction from clinic visit)

InfusionHypotension, #

Patient report of warmth? (select one)

InfusionWarmth, #

Patient report of any other symptoms? (select one) If 'yes', please record event on AE log

Other (specify): Value not provided

InfusionOther, #

YesNoS
1 = Yes
0 = No

NoWhy
1 = Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration)
90 = Other (specify)

MAGiC Study Drug Administration – 2nd Infusion:

Title: 2nd Infusion:

Study Drug Administration:

Did the study drug administration occur?

○ Yes ○ No * If yes, please answer the remaining questions on this tab.
If no, please provide a reason why.

MedAdminHappen, #

YesNo
1 = Yes
0 = No

If study drug was not administered, please provide reason why:

(select one)

WhyNoMedAdmin, #

Other (specify): | Value not provided

Study Drug Infusion Information:

Start Date: InfusionStartDay, # (MM-YYYY)   Start Time: InfusionStartTime, $5

Stop Date: InfusionStopDay, # (MMM-YYYY)   Stop Time: InfusionStopTime, $5

Total Dose: InfusionDose, # (mL)

Was infusion of the study drug slowed?

(select one) If yes, please document reason on AE and/or OOPS log.

InfusionSlowed, #

Infusion Vital Measurements:

DrugAdmin2_VS2

One set of vitals <u>MUST</u> be obtained <u>PRIOR</u> to starting the second study drug infusion.
Please record vitals every 20 minutes until 20 minutes after the completion of infusion.

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Heart Rate: (bpm)	Systolic BP: (mm/Hg)	Diastolic BP: (mm/Hg)	O2Sat: (%)	
VSDay, #	VSTime, $5	HeartRate, #	SBP, #	DBP, #	PulseOx, #	X

ADD

Study Drug Side Effects During <u>THIS</u> Infusion:

Did the patient experience any of the following:

Hypotension associated with infusion? (select one) (>20% SBP reduction from clinic visit)

InfusionHypotension, #

Patient report of warmth? (select one)

InfusionWarmth, #

Patient report of any other symptoms? (select one) If 'yes', please record event on AE log   Other (specify): | Value not provided

InfusionOther, #

YesNoS
1 = Yes
0 = No

NoWhy
1 = Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration)
90 = Other (specify)

MAGiC Study Drug Administration – 3rd Infusion:

◄ | **3rd Inf...(0/19)** | ► | -- Select to Jump -- | ▼

Title: 3rd Infusion:

Study Drug Administration:

Did the study drug administration occur?

○ Yes ○ No * If yes, please answer the remaining questions on this tab.
If no, please provide a reason why.

MedAdminHappen, #

YesNo
1 = Yes
0 = No

If study drug was not administered, please provide reason why:

(select one) ▼

WhyNoMedAdmin, #

Other (specify): | Value not provided

Study Drug Infusion Information:

Start Date | InfusionStartDay, # | -MMM-YYYY) | Start T | InfusionStartTime, $5 | H:MM)

Stop Date | InfusionStopDay, # | D-MMM-YYYY) | Stop T | InfusionStopTime, $5 | H:MM)

Total Dose: | InfusionDose, # | (mL)

Was infusion of the study drug slowed?

(select one) ▼ If yes, please document reason on AE and/or OOPS log.

InfusionSlowed, #

Infusion Vital Measurements:

One set of vitals **MUST** be obtained **PRIOR** to starting the third study drug infusion.
Please record vitals every 20 minutes until 20 minutes after the completion of infusion.

DrugAdmin3_VS3

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Heart Rate: (bpm)	Systolic BP: (mm/Hg)	Diastolic BP: (mm/Hg)	O2Sat: (%)	
VSDay, #	VSTime, $5	HeartRate, #	SBP, #	DBP, #	PulseOx, #	X

ADD

Study Drug Side Effects During THIS Infusion:

Did the patient experience any of the following:

Hypotension associated with infusion? | (select one) ▼ (>20% SBP reduction from clinic visit)

InfusionHypotension, #

Patient report of warmth? | (select one) ▼

InfusionWarmth, #

Patient report of any other symptoms? | (select one) ▼ If 'yes', please record event on AE log | Other (specify): | Value not provided

InfusionOther, #

YesNoS
1 = Yes
0 = No

NoWhy
1 = Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration)
90 = Other (specify)

MAGiC Study Drug Administration – 4th Infusion:

Title: 4th Infusion:

Study Drug Administration:

Did the study drug administration occur?

○ Yes ○ No * If yes, please answer the remaining questions on this tab. If no, please provide a reason why.

MedAdminHappen, #

YesNo
1 = Yes
0 = No

If study drug was not administered, please provide reason why:

(select one)

WhyNoMedAdmin, #

Other (specify): Value not provided

Study Drug Infusion Information:

Start Date: InfusionStartDay, # (D-MMM-YYYY) Start Time: InfusionStartTime, $5 (M)

Stop Date: InfusionStopDay, # (D-MMM-YYYY) Stop Time: InfusionStopTime, $5 (M)

Total Dose: InfusionDose, # (mL)

Was infusion of the study drug slowed?

(select one) If yes, please document reason on AE and/or OOPS log

InfusionSlowed, #

Infusion Vital Measurements:

DrugAdmin4_VS4

One set of vitals MUST be obtained PRIOR to starting the fourth study drug infusion.
Please record vitals every 20 minutes until 20 minutes after the completion of infusion.

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Heart Rate: (bpm)	Systolic BP: (mm/Hg)	Diastolic BP: (mm/Hg)	O2Sat: (%)	
VSDay, #	VSTime, $5	HeartRate, #	SBP, #	DBP, #	PulseOx, #	X

ADD

Study Drug Side Effects During THIS Infusion:

Did the patient experience any of the following:

Hypotension associated with infusion? (select one) (>20% SBP reduction from clinic visit)

InfusionHypotension, #

Patient report of warmth? (select one)

InfusionWarmth, #

Patient report of any other symptoms? (select one) Other (specify): Value not provided

If 'yes', please record event on AE log

InfusionOther, #

YesNoS
1 = Yes
0 = No

NoWhy
1 = Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration)
90 = Other (specify)

MAGiC Study Drug Administration – 5th Infusion:

Title: 5th Infusion:

Study Drug Administration:

Did the study drug administration occur?

○ Yes ○ No * If yes, please answer the remaining questions on this tab. If no, please provide a reason why.

MedAdminHappen, #

YesNo
1 = Yes
0 = No

If study drug was not administered, please provide reason why:

(select one)

WhyNoMedAdmin, #

Other (specify):

Value not provided

Study Drug Infusion Information:

Start Date	InfusionStartDay, # (-MMM-YYYY)	Start Time: InfusionStartTime, $5 (M)
Stop Date	InfusionStopDay, # (D-MMM-YYYY)	Stop Time: InfusionStopTime, $5 (M)
Total Dose:	InfusionDose, # (mL)	

Was infusion of the study drug slowed?

(select one) ▼ If yes, please document reason on AE and/or OOPS log

InfusionSlowed, #

Infusion Vital Measurements:

DrugAdmin5_VS5

One set of vitals <u>MUST</u> be obtained <u>PRIOR</u> to starting the fifth study drug infusion.
Please record vitals every 20 minutes until 20 minutes after the completion of infusion.

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Heart Rate: (bpm)	Systolic BP: (mm/Hg)	Diastolic BP: (mm/Hg)	O2Sat: (%)	
VSDay, #	VSTime, $5	HeartRate, #	SBP, #	DBP, #	PulseOx, #	X

ADD

Study Drug Side Effects During <u>THIS</u> Infusion:

Did the patient experience any of the following:

Hypotension associated with infusion? (select one) ▼ (>20% SBP reduction from clinic visit)

InfusionHypotension, #

Patient report of warmth? (select one) ▼

InfusionWarmth, #

Patient report of any other symptoms? (select one) ▼ If 'yes', please record event on AE log

Other (specify): Value not provided

InfusionOther, #

YesNoS
1 = Yes
0 = No

NoWhy
1 = Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration)
90 = Other (specify)

MAGiC Study Drug Administration – 6th Infusion:

Title: 6th Infusion:

Study Drug Administration:

Did the study drug administration occur?

○ Yes ○ No * If yes, please answer the remaining questions on this tab.
If no, please provide a reason why.

MedAdminHappen, #

YesNo
1 = Yes
0 = No

If study drug was not administered, please provide reason why:

(select one) WhyNoMedAdmin, #

Other (specify): Value not provided

Study Drug Infusion Information:

Start Date: InfusionStartDay, # (MMM-YYYY) Start Time: InfusionStartTime, $5

Stop Date: InfusionStopDay, # (D-MMM-YYYY) Stop Time: InfusionStopTime, $5

Total Dose: InfusionDose, # (mL)

Was infusion of the study drug slowed?

(select one) If yes, please document reason on AE and/or OOPS log. InfusionSlowed, #

Infusion Vital Measurements:

DrugAdmin6_VS6

One set of vitals MUST be obtained PRIOR to starting the sixth study drug infusion.
Please record vitals every 20 minutes until 20 minutes after the completion of infusion.

Date: (DD-MMM-YYYY)	Time: (HH:MM)	Heart Rate: (bpm)	Systolic BP: (mm/Hg)	Diastolic BP: (mm/Hg)	O2Sat: (%)	
VSDay, #	VSTime, $5	HeartRate, #	SBP, #	DBP, #	PulseOx, #	X

ADD

Study Drug Side Effects During THIS Infusion:

Did the patient experience any of the following:

Hypotension associated with infusion? (select one) (>20% SBP reduction from clinic visit) InfusionHypotension, #

Patient report of warmth? (select one) InfusionWarmth, #

Patient report of any other symptoms? (select one) If 'yes', please record event on AE log Other (specify): Value not provided

InfusionOther, #

YesNoS
1 = Yes
0 = No

morphine_equivalents, #

NoWhy
1 = Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration)
90 = Other (specify)

MAGiC Adverse Events Log:

Title: Adverse Events Log

Instructions: **An Adverse Event (AE) is an untoward medical occurrence experienced by a subject. An event constitutes a diagnosis, a set of related signs or sym** temporally associated with the use of an intervention whether or not it is related to the intervention.

In this study, any event that occurs from the time of randomization through hospital discharge, or day 7 of hospitalization whichever occurs first, is considere Abnormal laboratory tests are considered AE's if they are also considered clinically significant by the Principal Investigator.

Adverse Events Log:

AdverseEvent

Name of Event	Start Date: (DD-MMM-YYYY)	Stop Date: (DD-MMM-YYYY)	Outcome	Intensity
AEName, $100	AEStartDay, #	AEStopDay, #	(select o AEOutcome, #	(select one) AEIntensity, #

ADD

Outcome
1 = Death
2 = Recovered (patient returned to baseline)
3 = Recovered with sequelae
4 = Symptom persists

Intense
1 = Mild
2 = Moderate
3 = Severe

...ptoms, or a single sign or symptom

...AE.

AdverseEvent

Action taken:	If Action taken is"Other" describe other action taken	Relationship to Study Drug (Investigator assessment)	Was this event expected?	Is this a serious adverse event? If "yes", please complete a 'Serious Adverse Event' Report
(select one) AEActionTaken, #	Value not provided	(select one) DrugRelationship, #	(select one) AEExpected, #	(select one) AESeverity, #

Action
1 = Study medication infusion slowed
2 = Study medication discontinued
3 = Concomitant medication started, changed, or discontinued
4 = Surgery or other procedure
91 = None
90 = Other (describe)

Relation
1 = Not related
2 = Possibly related
3 = Probably related

Expect
1 = Expected
2 = Not Expected

YesNo
1 = Yes
0 = No

MAGiC PUD Annotated eCRF, Version 1.0

MAGiC Concomitant Medications Log:

ConMeds

Title: Concomitant Medications Log

Instructions: Record all concomitant medications administered from the time of randomization through hospital discharge or 12

Name of medication:	Total Dose:	Dose Unit:	Start Date: (DD-MMM-YYYY)
MedName, $255	MedDose, #	MedDoseUnit, $13	MedStartDay, #

ADD

ConMeds

...hours after the last IV opioid administration, whichever comes first.

Continuing?	Stop Date: (DD-MMM-YYYY)	Was the medication given in relation to an adverse event?	If yes, provide AE description:	
(select one)	MedStopDay, #	(select one)	MedIndication, $50	X

MedContinue, #

MedRelatedAE, #

YesNo
1 = Yes
0 = No

MAGiC Opioid Log:

Continu...(0/10)   Intermi...(0/7)   Opioids...(0/7)   -- Select to Jump --

Opioid_OpioidContinIV

Title: Opioids given continuously by IV (including PCA)

Instructions: Please record each continuous IV opioid (including PCA) received from the time of first study drug infusion through hospital discharge, or 12 hours after the last
All opioid doses must be recorded in the actual dose/units administered. No calculations or conversions should be made. All information recorded in this log must be obtained directly from the patient char

All continuous IV opioids must be totaled and recorded in **24 hour blocks** from the start date/time of the 1st infusion.

Name of Opioid:	Other name of opioid (specify):	Date started: (DD-MMM-YYYY)	Time started: (HHMM)	Date stopped: (DD-MMM-YYYY)	Time stopped: (HHMM)
(select one)					

IVOpioidName, #
IVOpioidNameOther, $255
IVOpioidStartDay, #
IVOpioidStartTime, $5
IVOpioidStopDay, #
IVOpioidStopTime, $5

MedName
1 = Morphine
2 = Hydromorphone
3 = Fentanyl
90 = Other (specify)

Continu...(0/10)   Intermi...(0/7)   Opioids...(0/7)   -- Select to Jump --

Opioid_OpioidContinIV

IV opioid administration, whichever comes first.
t.

Total dose given: BASAL	Total dose given: DEMAND	Dose unit:	Other dose unit (specify):	
		(select one)		X

IVOpioidDoseBasal, #
IVOpioidDoseDemand, #
IVOpioidDoseUnit, #
IVOpioidDoseUnitOther, S201

DoseUnit
1 = mg
2 = mcg
90 = other

Continu...(0/10)   Intermi...(0/7)   Opioids...(0/7)   -- Select to Jump --

Opioid_OpioidInterIV

Title: Opioids given intermittently by IV (excluding PCA)

Instructions: Please record each intermittent IV opioid (excluding PCA) received from the time of first study drug infusion through hospital discharge, or 12 hours after the last IV opioid administration, whichever comes first.
All opioid doses must be recorded in the actual dose/units administered. No calculations or conversions should be made. All information recorded in this log must be obtained directly from the patient chart.

Name of Opioid:	Other name of opioid(specify):	Date: (DD-MMM-YYYY)	Time given: (HHMM)	Total dose given:	Dose unit:	Other dose unit (specify):
						X
ADD						

BolusOpioidName, #
BolusOpioidNameOther, $255
BolusOpiodDay, #
BolusOpioidTime, $5
BolusOpioidDose, #
BolusOpioidDoseUnit, #
BolusOpioidDoseUnitOther, $201

Continu...(0/10) | Intermi...(0/7) | **Opioids...(0/7)** | ▶ -- Select to Jump -- ✓

Title: Opioids given Orally

Opioid_OpioidPO

Instructions: **Please record each oral opioid received from the time of first study drug infusion through hospital discharge, or 12 hours after the last IV opioid administration, whichever comes first.**
All opioid doses must be recorded in the actual dose/units administered. No calculations or conversions should be made. All information recorded in this log must be obtained directly from the patient chart.

Name of Opioid:	Other name of opioid (specify):	Date: (DD-MMM-YYYY)	Time given: (HHMM)	Total dose given:	Dose unit:	Other dose unit (specify):

POOpioidName, #

POOpioidNameOther, $255

POOpioidDay, #

POOpioidTime, $5

POOpioidDose, #

(select one)

POOpioidDoseUnit, #

POOpioidDoseUnitOther, $201

ADD

PONode
PONname
1 = Morphine
2 = Morphine SR
3 = Hydromorphone
4 = Codeine
5 = Oxycodone
90 = other (specify)

DoseUnit
1 = mg
2 = mcg
90 = other

MAGiC PUD Annotated eCRF, Version 1.0

MAGiC Ketorolac Log:

Ketorol...(0/5) ▶ -- Select to Jump --

Title: Ketorolac Log

Ketorolac

Instructions: **Record each dose of Ketorolac received from the time of randomization through hospital discharge or 12 hours after the last IV opioid administration, whichever comes first.**
Ketorolac is also known as: Acular, Acuvail, Sprix, and Toradol

Ketorolac Log

Date: (DD-MMM-YYYY)	Time given: (HHMM)	Total Dose:	Dose unit:	Other (specify):	
KetDay, #	KetTime, $5	KetDose, #	(select one)	KetDoseUnitOther, $201	X

ADD

KetDoseUnit, #

DoseUnit
1 = mg
2 = mcg
90 = other

MAGiC Blood Transfusion Log:

Blood T...(0/7) -- Select to Jump --

Transfusion

Title: Blood Transfusions Log

Instructions: **Please record all blood transfusions received from time of randomization through hospital discharge or 12 hours after the last IV opioid administration, whichever comes first.**

TypeBloodProductOther, $13

Start Date: (DD-MMM-YYYY)	Start Time: (HHMM)	Stop Date: (DD-MMM-YYYY)	Stop Time: (HHMM)	Type of Blood Product:	Other (specify):	Total Volume Infused: (mL)
TransStartDay, #	TransStartTime, $5	TransStopDay, #	TransStopTime, $5	select one)		TransfusionVolume, #

ADD

TypeBloodProduct, #

TypeBlod
1 = Packed RBC
90 = other (specify)

MAGiC Magnesium Log:

Magnesi...(0/3) ▶ -- Select to Jump --

Title: Magnesium Results

Please record the Magnesium result obtained from lab draw one hour after initiation of 4th study drug infusion here:

Date: Mg4Day, # (DD-MMM-YYYY)   Time: Mg4Time, $5 (HH:MM)   Magnesium: Magnesium4, # (mg/dL)

MAGiC Serious Adverse Event Report:

| SAEs (0/18) | Labs an...(0/11) | CDMCC (0/9) | ► | -- Select to Jump -- |

Title: Serious Adverse Event (SAE) Report

Instructions: Unique SAEs should be entered on separate forms. When multiple related events occur at the same time, a primary SAE should be entered and the remaining events should be listed in the narrative. Each event noted in the SAE report should have a corresponding entry on the AE log.

Date and time site became aware of SAE:

Date: SAEIDDay, # 📅 * (DD-MMM-YYYY)   Time: SAEIDTime, $5 (HHMM)

Date and time SAE report sent to CDMCC:

Date: SAERepDay, # 📅 * (DD-MMM-YYYY)   Time: SAERepTime, $5 (HHMM)

Primary serious adverse event:

There should be one primary medical term or condition or diagnosis if known.
This should correspond with an entry on AE log.

Name: SAEName, $400 *

Date and time SAE started:

Date: SAEOnsetDay, # * (DD-MMM-YYYY)   Time: SAEOnsetTime, $5 (HHMM)

Date and time SAE resolved (if applicable):

Date: SAEResDay, # (DD-MMM-YYYY)   Time: SAEResTime, $5 (HHMM)

Criteria for Seriousness - Enter all that apply

SAE_Serious

| Criteria for seriousness: | If "Other", describe: | |
| (select one) SAECriteria, # ▼ | Value not provided | |

ADD

Criteria
1 = Death
2 = Life threatening
3 = Inpatient hospitalization
4 = Prolonged existing hospitalization
5 = Persistent or significant disability or incapacity
6 = Congenital abnormality or birth defect
90 = Other (specify)

Action taken because of serious adverse event:

(select one) SAEAction, # ▼ *

If "Other", describe: Value not provided

Action
1 = Study medication infusion slowed
2 = Study medication discontinued
3 = Concomitant medication started, changed, or discontinued
4 = Surgery or other procedure
91 = None
90 = Other (describe)

If the study drug was discontinued due to this SAE, did the event abate after stopping the study drug?

SAEAbate, # ○ Yes * ○ No ○ Not applicable

YesNoNA
1 = Yes
0 = No
96 = Not applicable

Outcome of serious adverse event:

(select one) ▼ SAEOutcome, #

Outcome
1 = Death
2 = Recovered (patient returned to baseline)
3 = Recovered with sequelae
4 = Symptom persists

Intensity of serious adverse event:

○ Mild * SAEIntensity, # ○ Moderate ○ Severe

Intense
1 = Mild
2 = Moderate
3 = Severe

Relationship to study drug:
(Investigator assessment)

○ Not related * SAERelation, # ○ Possibly related ○ Probably related

Relation
1 = Not related
2 = Possibly related
3 = Probably related

Was the SAE expected?

○ Expected * SAEExpected, # ○ Not expected

Expect
1 = Expected
2 = Not expected

SAEs (0/18) | Labs an...(0/11) | **CDMCC (0/9)** | ► | -- Select to Jump --

Title: CDMCC Review

Instructions: *This section is for CDMCC use only.*

Date the event was reviewed by medical monitor:

Date: | MMReviewDay, # | (DD-MMM-YYYY)

Is event described in sufficient detail to allow an informed review of the occurrence?

○ Yes ○ No | SAEDetail, #

Does the event require changes to the protocol to minimize further risk?

○ Yes ○ No | SAEProtocol, #

Does the event require changes to the consent documents?

○ Yes ○ No | SAEInformConsent, #

Will this event require reconsent of current participants?

○ Yes ○ No | SAEReinformConsent, #

Does the event require expedited reporting to the DSMB and NICHD?

○ Yes ○ No | SAENotify, #

Is the overall risk/benefit relationship of the research still acceptable in light of information in this report?

○ Yes ○ No | SAEStudyCont, #

Was the event downgraded to a non-serious adverse event?

○ Yes ○ No | NonSAE, #

YesNo
1 = Yes
0 = No

CDMCC narrative or comments:

Value not provided

MAGiC Study Summary:

◄ **Study S...(0/9)** ► -- Select to Jump -- ▼

Title: Study Summary

Instructions: **This form is to be completed at hospital discharge OR 12 hours after last IV opioid administration.**

Record date/time of Hospital Discharge:

DischargeTime, $5

DischargeDay, #

Date: [_____] 📅 * (DD-MMM-YYYY)   Time: [_____] (HHMM)

Record date/time of *FIRST* IV opioid administration received by patient:

FirstIVOpioidTime, $5

FirstIVOpioidDay, #

Date: [_____] 📅 * (DD-MMM-YYYY)   Time: [_____] (HHMM)

Record date/time of *LAST* IV opioid administration received by patient:

LastIVOpioidTime, $5

LastIVOpioidDay, #

Date: [_____] 📅 * (DD-MMM-YYYY)   Time: [_____] (HHMM)

Which study drug does the patient believe s/he received?

PtDrugAssess, #

○ Magnesium ○ Saline ○ Patient does not know ○ Not Asked *

Was the final diagnosis of the patient vasoocclusive crisis?

FinalDiagnosis, #

○ Yes ○ No *   If the final diagnosis was not vasoocclusive crisis, what was the cause of the pain (specify)?

FinalDiagnosisOther, $1513

[_____]

YesNo
1 = Yes
0 = No

DrugOn
1 = Magnesium
2 = Saline
92 = Patient does not know
99 = Not Asked

MAGiC Telephone Follow-up:

| Phone FU (0/22) | Parent ...(0/11) | Child S...(0/4) | ► | -- Select to Jump -- |

Title: Telephone Follow-up

Instructions: Telephone follow-up must be completed within 8 to 10 days following discharge. Five attempts MUST be made before attempts to contact the family may be abandoned.

Was the telephone follow-up attempted?

○ Yes ○ No * — PhoneOccur, # — YesNo / 1 = Yes / 0 = No

If NO, please specify why the telephone follow-up was not attempted: — Value not provided

Date: (DD-MMM-YYYY)	Time: (HHMM)	What resulted from this attempt to contact the patient/parent?	
Value not provided	Value not provided	Value not provided	X

ADD

Was the parent interview completed? (select one) — ParentInterview, #   If NO, please explain: Value not provided   (e.g. Parent had to get off the phone before interview was completed...)

YesNoS / 1 = Yes / 0 = No

Was the child interview completed? (select one) — ChildInterview, #   If NO, please explain: Value not provided   (e.g. Child was never available...)

Rehospitalization Information:

Was the patient rehospitalized within 7 days after discharge from the hospital?
(All-cause and sickle-cell related hospitalizations are to be included)

Rehosp7day, # — YesNoS / 1 = Yes / 0 = No

(select one)   If yes, provide the following information.

Date Rehospitalized: (DD-MMM-YYYY)	Time Rehospitalized: (HHMM)	Date Discharged: (DD-MMM-YYYY)	Location of rehospitalization:	From what source was the rehospitalization information obtained?	Please provide a brief description of the event requiring rehospitalization of patient?
RehospDay, #	RehospTime, $5	RehospDischargeDay, #	(select one) — RehospLoc, #	(select one) — RehospSource, #	Value not provided

Phone_PhoneRehos

Rehos / 1 = Study Hospital / 2 = Other Hospital

Unscheduled Care Information:

Did the patient have the need for unscheduled care within 7 days after discharge from the hospital?

Unsched7day, # — YesNoS / 1 = Yes / 0 = No

(select one)   If yes, provide the following information.

Date: (DD-MMM-YYYY)	Where was the unscheduled care received?	Other (specify):	From what source was the unscheduled care information obtained?	Please provide a brief description of the event patient required unscheduled care for?	
UnschedDay, #	(select one) — UnschedLoc, #	UnschedLocOther, $201	(select one) — UnschedSource, #	Value not provided	X

Phone_PhoneUnsched

UnCare
1 = ED/Emergent Care
2 = Primary Care Physician office
3 = Clinic
90 = Other (specify)

Source
1 = Parent
2 = Chart
3 = Parent & Chart

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Phone FU (0/18)   **Parent ...(0/11)**   Child S...(0/4)   ▶   -- Select to Jump -- ▼

Title: Short Term Outcomes: ***Parent Response***

Instructions: **Please answer the following questions pertaining to your child's experience 8 to 10 days post hospital discharge.**

Days of daycare, school, or work missed post hospital discharge:

Is your child currently in a formal school setting?

School, #   (select one) ▼   If *YES*, provide response for number of days of school missed
If *NO*, skip to daycare question

If *YES*, how many days of school have been missed by your child since discharge from the hospital?   (select one) ▼   **MissedSchool, #**

> **DaysA**
> 1 = None
> 2 = 1 to 3 days
> 3 = 4 to 6 days
> 4 = > 6 days

Is your child in daycare?

Daycare, #   (select one) ▼   If *YES*, provide response for number of days of daycare missed
If *NO*, skip to unable to play question

If *YES*, how many days of daycare have been missed by your child since discharge from the hospital?   (select one) ▼   **MissedDaycare, #**

> **YesNoS**
> 1 = Yes
> 0 = No

If your child is *NOT* currently in a formal school or daycare setting (i.e. summer or too young), how many days has your child been unable to play or perform their usual activities?

UnableToPlay, #   (days)

Is the parent/primary caretaker currently working or in school?

CaretakerWork, #   (select one) ▼   If *YES*, provide response for number of days of work missed
If *NO*, skip to pain questions

If *YES*, how many days of work/school have been missed by the parent/primary caretaker since child's discharge from the hospital?   (select one) ▼   **MissedCaretakerWork, #**

Pain *after* hospital discharge:

How many days of pain has your child experienced after hospital discharge? Please record the *exact* number of days.   (days) **OR**   **ParentDaysOfPainExact, #** | If you are unable to provide an exact number of days of pain, please provide a range for days of pain.   (select one) ▼   **ParentDaysOfPainRange, #**

> **DaysB**
> 2 = 1 to 3 days
> 3 = 4 to 6 days
> 4 = > 6 days

If your child has experienced at least one day of pain since hospital discharge, answer the following question.

On a scale of 0 to 10, with 10 being the worst pain and 0 being no pain, how would you rate your child's pain right now, today?

(select one) ▼   **ParentPainScale, #**

If rating of pain is greater than 0 (zero), please answer the last question.

As the parent/primary caregiver, from your perspective, how would you rate the overall pain relief your child has received since hospital discharge?

(select one) ▼   **ParentChildOverallPain, #**

> **OneToTen**
> 0 = 0
> 1 = 1
> 2 = 2
> 3 = 3
> 4 = 4
> 5 = 5
> 6 = 6
> 7 = 7
> 8 = 8
> 9 = 9
> 10 = 10

> **PainScal**
> 1 = Excellent
> 2 = Good
> 3 = Adequate
> 4 = Some
> 5 = None

◄ | Phone FU (0/18) | Parent ...(0/11) | **Child S...(0/4)** | ► | -- Select to Jump --

Title: Short Term Outcomes: ***Child Response***

Instructions: **Please answer the following questions pertaining to your experience 8 to 10 days post hospital discharge.**

Pain *after* hospital discharge:

How many days of pain have you experienced after hospital discharge? Please record the *exact* number of days.

ChildDaysOfPainExact, #

(days) **OR**

If you are unable to provide an exact number of days of pain, please provide a range for days of pain.

(select one)

ChildDaysOfPainRange, #

If you have experienced at least one day of pain since hospital discharge, answer the following question.

On a scale of 0 to 10, with 10 being the worst pain and 0 being no pain, how would you rate your pain right now, today?

(select one)

ChildPainScale, #

If rating of pain is greater than 0 (zero) *and* you are between 5 and 18 years of age, please answer the last question.

From your perspective, how would you rate your overall pain relief received since discharge?

(select one)

OlderChildOverallPain, #

PainScal
1 = Excellent
2 = Good
3 = Adequate
4 = Some
5 = None

OneToTen
0 = 0
1 = 1
2 = 2
3 = 3
4 = 4
5 = 5
6 = 6
7 = 7
8 = 8
9 = 9
10 = 10

DaysB
2 = 1 to 3 days
3 = 4 to 6 days
4 = > 6 days

MAGiC Telephone Follow-up Ages 4-18:

| Phone FU (0/22) | Parent ...(0/11) | Child S...(0/4) | ► | -- Select to Jump -- |

Title: Telephone Follow-up

Instructions: Telephone follow-up must be completed within 8 to 10 days following discharge. Five attempts MUST be made before attempts to contact the family may be abandoned.

Was the telephone follow-up attempted?

○ Yes ○ No *

PhoneOccur, #

YesNo
1 = Yes
0 = No

If NO, please specify why the telephone follow-up was not attempted:

Value not provided

Date: (DD-MMM-YYYY)	Time: (HHMM)	What resulted from this attempt to contact the patient/parent?	
Value not provided	Value not provided	Value not provided	X

Was the parent interview completed? (select one) If NO, please explain: Value not provided (e.g. Parent had to get off the phone before interview was completed...)

ParentInterview, #

YesNoS
1 = Yes
0 = No

Was the child interview completed? (select one) If NO, please explain: Value not provided (e.g. Child was never available...)

ChildInterview, #

Rehospitalization Information:

Was the patient rehospitalized within 7 days after discharge from the hospital?
(All-cause and sickle-cell related hospitalizations are to be included)

(select one)

Rehosp7day, #

YesNoS
1 = Yes
0 = No

If yes, provide the following information.

Date Rehospitalized: (DD-MMM-YYYY)	Time Rehospitalized: (HHMM)	Date Discharged: (DD-MMM-YYYY)	Location of rehospitalization:	From what source was the rehospitalization information obtained?	Please provide a brief description of the event requiring rehospitalization of patient?
RehospDay, #	RehospTime, $5	RehospDischargeDay, #	(select one) RehospLoc, #	(select one) RehospSource, #	Value not provided

Phone_PhoneRehos

Rehos
1 = Study Hospital
2 = Other Hospital

Unscheduled Care Information:

Did the patient have the need for unscheduled care within 7 days after discharge from the hospital?

(select one)

Unsched7day, #

YesNoS
1 = Yes
0 = No

If yes, provide the following information.

Date: (DD-MMM-YYYY)	Where was the unscheduled care received?	Other (specify):	From what source was the unscheduled care information obtained?	Please provide a brief description of the event patient required unscheduled care for?	
UnschedDay, #	(select one) UnschedLoc, #	UnschedLocOther, $201	(select one) UnschedSource, #	Value not provided	X

Phone_PhoneUnsched

UnCare
1 = ED/Emergent Care
2 = Primary Care Physician office
3 = Clinic
90 = Other (specify)

Source
1 = Parent
2 = Chart
3 = Parent & Chart

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◄ | Phone FU (0/18) | **Parent ...(0/11)** | Child S...(0/4) | ► | -- Select to Jump -- ▼

Title: Short Term Outcomes: ***Parent Response***

Instructions: **Please answer the following questions pertaining to your child's experience 8 to 10 days post hospital discharge.**

Days of daycare, school, or work missed post hospital discharge:

Is your child currently in a formal school setting?

School, # | (select one) ▼ If *YES*, provide response for number of days of school missed
If *NO*, skip to daycare question

If *YES*, how many days of school have been missed by your child since discharge from the hospital? | (select one) ▼
MissedSchool, #

DaysA
1 = None
2 = 1 to 3 days
3 = 4 to 6 days
4 = > 6 days

Is your child in daycare?

Daycare, # | (select one) ▼ If *YES*, provide response for number of days of daycare missed
If *NO*, skip to unable to play question

If *YES*, how many days of daycare have been missed by your child since discharge from the hospital? | (select one) ▼
MissedDaycare, #

YesNoS
1 = Yes
0 = No

If your child is *NOT* currently in a formal school or daycare setting (i.e. summer or too young), how many days has your child been unable to play or perform their usual activities?

UnableToPlay, # | (days)

Is the parent/primary caretaker currently working or in school?

CaretakerWork, # | (select one) ▼ If *YES*, provide response for number of days of work missed
If *NO*, skip to pain questions

If *YES*, how many days of work/school have been missed by the parent/primary caretaker since child's discharge from the hospital? | (select one) ▼
MissedCaretakerWork, #

Pain *after* hospital discharge:

How many days of pain has your child experienced after hospital discharge? Please record the *exact* number of days. | (days) **OR**
ParentDaysOfPainExact, #

If you are unable to provide an exact number of days of pain, please provide a range for days of pain. | (select one) ▼
ParentDaysOfPainRange, #

DaysB
1 = 0
2 = 1-3 days
3 = 4-6 days
4 = > 6 days

Since your child has left the hospital, how has your child's pain been?

ParentChildOverallPain_v2, # | (select one) ▼

On a scale of 0 to 10, with 10 being the worst pain and 0 being no pain, how would you rate your child's pain right now, today?

(select one) ▼ | ParentPainScale, #

OneToTen
0 = 0
1 = 1
2 = 2
3 = 3
4 = 4
5 = 5
6 = 6
7 = 7
8 = 8
9 = 9
10 = 10

PainScalNew
1 = Much better
2 = A little better
3 = The same
4 = A little worse
5 = Much worse
6 = No pain since discharge

Phone FU (0/22)   Parent ...(0/11)   **Child S...(0/4)** ▶   -- Select to Jump --

Title: Short Term Outcomes: ***Child Response***

Instructions: **Please answer the following questions pertaining to your experience 8 to 10 days post hospital discharge.**

Pain *after* hospital discharge:

Starting the morning following the day of hospital discharge, on how many days have you experienced pain? Please record *exact* number of days.   [_____] (days) **OR**

ChildDaysOfPainExact, #

If you are unable to provide the exact number of days of pain, please provide a range for days of pain.   (select one) ▼

ChildDaysOfPainRange, #

Since you left the hospital, how has your pain been?

OlderChildOverallPain_v2, #

(select one) ▼

On a scale of 0 to 10, with 10 being the worst pain and 0 being no pain, how would you rate your pain right now, today?

(select one) ▼   ChildPainScale, #

PainScalNew
1 = Much better
2 = A little better
3 = The same
4 = A little worse
5 = Much worse
6 = No pain since discharge

OneToTen
0 = 0
1 = 1
2 = 2
3 = 3
4 = 4
5 = 5
6 = 6
7 = 7
8 = 8
9 = 9
10 = 10

DaysB
1 = 0
2 = 1-3 days
3 = 4-6 days
4 = > 6 days

MAGiC Telephone Follow-up Ages 19-21:

Phone FU (0/21) | Short T...(0/8) | -- Select to Jump --

Title: Telephone Follow-up

Instructions: Telephone follow-up must be completed within 8 to 10 days following discharge. Five attempts MUST be made before attempts to contact the patient may be abandoned.

Was the telephone follow-up attempted?

○ Yes ○ No

PhoneOccur, #

YesNo
1 = Yes
0 = No

If NO, please specify why the telephone follow-up was not attempted:

Value not provided

Date: (DD-MMM-YYYY)	Time: (HHMM)	What resulted from this attempt to contact the patient?	Notes/Comments:
Value not provided	Value not provided	Value not provided	Value not provided

ADD

Was the patient interview completed? (select one) ▾

YesNoS
1 = Yes
0 = No

PatientInterview, #

If NO, please explain: (e.g. Patient was never available...)

Value not provided

Rehospitalization Information:

Was the patient rehospitalized within 7 days after discharge from the hospital?
(All-cause and sickle-cell related hospitalizations are...)

(select one) ▾

Rehosp7day, #

YesNoS
1 = Yes
0 = No

Date Rehospitalized: (DD-MMM-YYYY)	Time Rehospitalized: (HHMM)	Date Discharged: (DD-MMM-YYYY)	Location of rehospitalization:	From what source was the rehospitalization information obtained?	Provide a brief description of the event requiring rehospitalization of patient:
RehospDay, #	RehospTime, $5	RehospDischargeDay, #	(select one) ▾ — RehospLoc, #	(select one) ▾ — RehospSource, #	Value not provided

PhoneAdult_PhoneRehos

Rehos
1 = Study Hospital
2 = Other Hospital

Sources
1 = Patient
2 = Chart
3 = Patient and Chart

Unscheduled Care Information:

Did the patient have the need for unscheduled care within 7 days after discharge from the hospital?

YesNoS
1 = Yes
0 = No

Unsched7day, #

...es, provide the following information:

Date: (DD-MMM-YYYY)	Where was the unscheduled care received?	Other (specify):	From what source was the unscheduled care information obtained?	Provide a brief description of the event patient required unscheduled care for:
UnschedDay, #	(select one) ▾ — UnschedLoc, #	UnschedLocOther, $13	(select one) ▾ — UnschedSource, #	Value not provided

PhoneAdult_PhoneUnsched

UnCare
1 = ED/Emergent Care
2 = Primary Care Physician office
3 = Clinic
90 = Other (specify)

Sources
1 = Patient
2 = Chart
3 = Patient and Chart

◄ Phone FU (0/21) **Short T...(0/8)** ► -- Select to Jump -- ▼

Title: Short Term Outcomes

Instructions: **Please answer the following questions pertaining to your experience 8 to 10 days post hospital discharge.**

Days of school or work missed post-hospital discharge:

Are you currently in school?

YesNoS
1 = Yes
0 = No

School, #

(select one) ▼

If *YES*, how many days of school have you missed since being discharged from the hospital?

(select one) ▼

MissedSchool, #

DaysA
1 = None
2 = 1 to 3 days
3 = 4 to 6 days
4 = > 6 days

Are you currently working?

YesNoS
1 = Yes
0 = No

Work, #

(select one) ▼

If *YES*, how many days of work have you missed since being discharged from the hospital?

(select one) ▼

MissedWork, #

DaysA
1 = None
2 = 1 to 3 days
3 = 4 to 6 days
4 = > 6 days

Pain after hospital discharge:

Starting the morning following the day of hospital discharge, on how many days have you experienced pain? Please record *exact* number of days.

[   ] (days) **OR**

DaysOfPainExact, #

If you are unable to provide the exact number of days of pain, please provide a range for days of pain:

(select one) ▼

DaysOfPainRange, #

DaysB
1 = 0 days
2 = 1 to 3 days
3 = 4 to 6 days
4 = > 6 days

Since you left the hospital, how has your pain been?

OverallPain, #

(select one) ▼

On a scale of 0 to 10, with 10 being the worst pain and 0 being no pain, how would you rate your pain right now, today?

(select one) ▼

PainScale, #

PainScalNew
1 = Much better
2 = A little better
3 = The same
4 = A little worse
5 = Much worse
6 = No pain since discharge

OneToTen
0 = 0
1 = 1
2 = 2
3 = 3
4 = 4
5 = 5
6 = 6
7 = 7
8 = 8
9 = 9
10 = 10

MAGiC Follow-Up Visit:

| Follow-...(0/15) | Labs (0/9) | ► | -- Select to Jump -- |

Title: Follow-up Visit

Did the patient return for the follow-up visit?

○ Yes ○ No *

YesNo
1 = Yes
0 = No

FUOccur, #

If NO, please specify why the patient did not return:

Value not provided

Date of Follow-up Visit:

Date: FUDay, # (DD-MMM-YYYY)

Rehospitalization Information:

Was patient rehospitalized between 8 and 28 days after discharge from the hospital?
(All-cause and sickle-cell related hospitalizations are to be included)

(select one)   Rehosp8to28day, #

YesNoS
1 = Yes
0 = No

If yes, provide the following information.

Date Rehospitalized: (DD-MMM-YYYY)	Date Discharged: (DD-MMM-YYYY)	Location of rehospitalization:	From what source was the rehospitalization information obtained?	Please provide a brief description of the event requiring rehospita
RehospDay, #	RehospDischargeDay, #	(select one) RehospLoc, #	(select one) RehospSource, #	Value not provided

FollowUp_Rehos

Rehos
1 = Study Hospital
2 = Other Hospital

Unscheduled Care Information:

Did patient have the need for unscheduled care between 8 and 28 days after discharge from the hospital?

(select one)   Unsched8to28day, #

YesNoS
1 = Yes
0 = No

If yes, provide the following information.

Date: (DD-MMM-YYYY)	Where was the unscheduled care received?	Other (specify):	From what source was the unscheduled care information obtained?	Please provide a brief description of the event requiring unscheduled c
UnschedDay, #	(select one) UnschedLoc, #	UnschedLocOther, $19	(select one) UnschedSource, #	Value not provided

FollowUp_Unsched

UnCare
1 = ED/Emergent Care
2 = Primary Care Physician Office
3 = Clinic
4 = Other (specify)

Source
1 = Parent
2 = Chart
3 = Parent & Chart

| Follow-...(0/15) | Labs (0/9) | ► | -- Select to Jump -- |

Title: Follow-up Labs

Were Follow-up labs drawn?

(select one)   FULabsDone, #

YesNoS
1 = Yes
0 = No

Date and Time of Follow-up Lab Result(s):

Date: FULabDay, # (DD-MMM-YYYY)

Time: FULabTime, $5 (HHMM)

Hematocrit: (%)	Hgb: (g/100mL)	WBCs: (x 10^3/uL)	Platelets: (x 10^3/uL)	Reticulocytes: (%)	Lactate dehydrogenase: (IU/L)	
Hematocrit, #	Hemoglobin, #	WBC, #	Platelets, #	Reticulocytes, #	LDH, #	X

ADD

FollowUp_FULabs

LostSTO, #

LostPain, #

LostCall
0 = Not lost to follow-up
1 = Lost to follow-up
W = Withdrew from follow-up
I = Ineligible for study

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MAGiC Blood Transfusions Post Hospital Discharge:

Blood T...(0/7)

Title: Blood Transfusions

Did the patient have a biomarker sample obtained for the follow-up visit timepoint?

(select one) ▼ * Biomarker, #

YesNoC
1 = Yes; complete the next question
0 = No; no further data collection on this form is required

Did the patient receive any blood transfusions after hospital discharge but before the follow-up visit biomarker sample was obtained?

(select one) ▼ BloodTrans, #

YN
1 = Yes; complete the following information
0 = No; no further data collection on this form is required

Blood Transfusion Information

Date of most recent blood transfusion: BloodTransDay, # (DD-MMM-YYYY)

Type
1 = Packed RBC
90 = Other (specify)
92 = Unknown

Type of blood product: BloodTransType, # Other type of blood product: BloodTransTypeOth, $25

From what source was the transfusion information obtained? BloodTransSource, # Location of transfusion: BloodTransLoc, #

Source
1 = Parent
2 = Chart
3 = Parent & Chart

Loc
1 = Study hospital
2 = Other hospital

MAGiC Day 28 Patient Mortality:

Title: Patient Status

Instructions: *Please Note:* The patient's vital status must be established on or after Day 28. This form must be completed at the time of the follow-up visit. If the follow-up visit does not occur due to patient not returning for their visit, this form should be completed at the time the follow-up visit would have been completed. If the patient withdraws their consent for ALL study related procedures, this form must be completed at the time of withdrawal.

Date Patient Vital Status Determined:

DayDetermined, #   * (DD-MMM-YYYY)

Patient Vital Status:

(select one) *   VitalStatus, #

Status
1 = Alive
2 = Dead
93 = Unable to determine

Patient Vital Status Date:

This is the last date the patient was known to, or is documented as being alive.
If the patient's vital status is dead, please complete the death information form.

AliveStatusDay, #   (DD-MMM-YYYY)

MAGiC Withdrawal of Consent:

WoC (0/4) ▶ -- Select to Jump --

Title: Withdrawal of Consent

What elements of consent did the patient/parent withdraw?

(select one) | ElementsWithdrawn, # | *

Date consent was withdrawn: | DayConsentWithdrawn, # | * (DD-MMM-YYYY)

Time consent was withdrawn: | TimeConsentWithdrawn, $5 | (HHMM)

Reason provided for why consent was withdrawn:

ReasonConsentWithdrawn, $409

WOC
1 = Withdrew consent to continue on study medication; obtaining blood samples and data collection can continue
2 = Withdrew consent for study medication and obtaining of blood samples; data collection to continue
3 = Withdrew consent to obtain blood samples; study medication and data collection can continue
4 = Withdrew consent for study medication, blood samples, and data collection to continue, except AEs and follow up
5 = Withdrew consent for study medication, blood samples, data collection, and any contact or follow up

Biomarkers:

Variable	Format	Type	Label	Algorithm / Notes
Draw_Code		$50	Draw code	
sP_selectin		#	Plasma level of sP-selectin	= 0.01 if sP_selectinRaw is .o = sP_selectinRaw otherwise
sVCAM_1		#	Plasma level of sVCAM-1	= 0.01 if sVCAM_1Raw is .o = sVCAM_1Raw otherwise
Nitrite		#	Plasma nitrite	= 0.01 if NitriteRaw is .o = NitriteRaw otherwise
IL_1b		#	Plasma level of IL-1\beta	= 0.01 if IL_1bRaw is .o = IL_1bRaw otherwise
IL_6		#	Plasma level of IL-6	= 0.01 if IL_6Raw is .o = IL_6Raw otherwise
TNFa		#	Plasma level of TNF-\alpha	= 0.01 if TNFaRaw is .o = TNFaRaw otherwise
IFNg		#	Plasma level of IFN-\gamma	= 0.01 if IFNgRaw is .o = IFNgRaw otherwise

Pain Scores:

Variable	Format	Type	Label	Algorithm / Notes
FirstPainScore		#	First pain score	
LastPainScore		#	Last pain score	
FUPainYN		#	FU pain score available	
FUPainScore		#	FU pain score	

Visit
0 = Time 0 - Prior to 1st study drug infusion
1 = Time 1 - After last dose of study drug
2 = Time 2 - Telephone follow-up
3 = Time 3 - Follow-up visit

QL Scores:

Variable	Format	Type	Label	Algorithm / Notes
Visit	Visit	#	Please indicate at which visit this survey was completed	
c_PainHurt		#	Child: Pain and Hurt Summary	
c_PainImpact		#	Child: Pain Impact Summary	
c_WorryI		#	Child: Worry Summary (I)	
c_WorryII		#	Child: Worry Summary (II)	
c_Emotions		#	Child: Emotions Summary	
c_PainManagement		#	Child: Pain Management Summary	
c_Treatment		#	Child: Symptoms and Treatment Summary	
c_CommunicationI		#	Child: Communication Summary (I)	
c_CommunicationII		#	Child: Communication Summary (II)	
c_SickleCell		#	Child: PedsQL Sickle Cell	
c_General		#	Child: General Fatigue Summary	
c_Sleep		#	Child: Sleep and Rest Fatigue Summary	

Variable	Format	Type	Label	Algorithm / Notes
c_Cognitive		#	Child: Cognitive Fatigue Summary	
c_Fatigue		#	Child: PedsQL Fatigue	
c_Physical		#	Child: Physical Functioning Summary	
c_Emotional		#	Child: Emotional Functioning	
c_Social		#	Child: Social Functioning	
c_School		#	Child: School Functioning	
c_Psychosocial		#	Child: Psychosocial Score	
c_Generic		#	Child: PedsQL Generic	
p_PainHurt		#	Parent: Pain and Hurt Summary	
p_PainImpact		#	Parent: Pain Impact Summary	
p_WorryI		#	Parent: Worry Summary (I)	
p_WorryII		#	Parent: Worry Summary (II)	
p_Emotions		#	Parent: Emotions Summary	
p_PainManagement		#	Parent: Pain Management Summary	
p_Treatment		#	Parent: Symptoms and Treatment Summary	

Variable	Format	Type	Label	Algorithm / Notes
p_CommunicationI		#	Parent: Communication Summary	
p_CommunicationII		#	Parent: Communication Summary	
p_SickleCell		#	Parent: PedsQL Sickle Cell	
p_General		#	Parent: General Fatigue Summary	
p_Sleep		#	Parent: Sleep and Rest Fatigue Summary	
p_Cognitive		#	Parent: Cognitive Fatigue Summary	
p_Fatigue		#	Parent: PedsQL Fatigue	
p_Physical		#	Parent: Physical Functioning Summary	
p_Emotional		#	Parent: Emotional Functioning	
p_Social		#	Parent: Social Functioning	
p_School		#	Parent: School Functioning	
p_Psychosocial		#	Parent: Psychosocial Score	
p_Generic		#	Parent: PedsQL Generic	
Occurrence		#	Occurrence	

MAGIC Peds Quality of Life Family Information Form Ages 4-18:

◄ FamilyI...(0/25) ► -- Select to Jump --

Title: Family Information Form

Basic Information:

What is your relationship to this child?

RelationChild, #   Other, please specify: RelationChildOther, $8

Relate
1 = Mother, Step Mother, Foster Mother
2 = Father, Step Father, Foster Father
3 = Grandmother
4 = Grandfather
5 = Guardian
90 = Other

Information About Mother:

MomMaritalStatus, #   Marital Status: (select one)   Highest Level of Education: MomEducation, #   Occupation or Job Title: Value not provided

Information About Father:

DadMaritalStatus, #   Marital Status: (select one)   Highest Level of Education: DadEducation, #   Occupation or Job Title: Value not provided

Marital
1 = Single
2 = Married
3 = Separated
4 = Living with someone
5 = Divorced
6 = Widowed

In the past 6 months, has your child...

Had a **chronic health condition** (defined as a physical or mental health condition that has lasted or is expected to last at least 6 months, and interferes with your child's activities)?

(select one)   ChronicCondition, #   YesNoS
1 = Yes
0 = No

If YES, what is the name of your child's chronic health condition? (please list all conditions)

Value not provided   X

ADD

Educate
1 = 6th grade or less
2 = 7th - 9th grade
3 = 10th - 12th grade
4 = High school graduate
5 = Some college or certification course
6 = College graduate
7 = Graduate or Professional degree

In the past 12 months, has your child had...

Any **overnight visits** to the hospital?

HospitalVisits, #   (select one) If YES...

How many ti...   NumberHospitalVisits, #   How many tim...   NumHospVisitsPain, #   How many times were for chest crisis?   NumHospVisitsACS, #

YesNoS
1 = Yes
0 = No

Any **emergency room / urgent care** visits not resulting in hospitalization?

EDVisits, #   (select one) If YES...

How many times total?   NumberEDVisits, #   How many times were for pain?   NumEDVisitsPain, #   How many times were for chest crisis?   NumEDVisitsACS, #

In the past 30 days...

How many days did your child miss from school due to physical or mental health?

DaysMissSchool, #   # of days

How many days was your child sick in bed or too ill to play?

DaysSick, #   # of days

How many days did your child need someone to care for him/her due to physical or mental health?

DaysChildcare, #   # of days

Parent's Work

Do you work outside the home?

YesNoS
1 = Yes
0 = No

ParentNotWork, #   (select one) If yes, please answer the following questions about your work.

In the past **30 days**, how many days have you missed from work due to your child's physical or mental health?

ParentMissWork, #   # of days

In the past **30 days**, has your child's health interfered with...

Your daily routine at work?   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered   ParentRoutine, #

Your ability to concentrate at work?   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered   ParentConcentrate, #

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

MAGiC PUD Annotated eCRF, Version 1.0

MAGIC Peds Quality of Life Adult Patient Information Form Ages 19-21:

AdultIn...(0/18)   -- Select to Jump --

Title: Adult Patient Information Form

Information About Patient:

MaritalStatus, #

Marital Status: (select one)   Highest Level of (select one) Education: Occupation or Job Title:

Education, #

Value not provided

Marital
1 = Single
2 = Married
3 = Separated
4 = Living with someone
5 = Divorced
6 = Widowed

Impact Scale:

In the past 6 months, have you...

Had a chronic health condition (defined as a physical or mental health condition that has lasted or is expected to last at least 6 months)?

(select one)

ChronicCondition, #

If YES, what is the name of your chronic health condition? (please list all conditions)

Value not provided   X

ADD

YesNoS
1 = Yes
0 = No

Educate
1 = 6th grade or less
2 = 7th - 9th grade
3 = 10th - 12th grade
4 = High school graduate
5 = Some college or certification course
6 = College graduate
7 = Graduate or Professional degree

In the past 12 months, have you had...

Any **overnight visits** to the hospital?

HospitalVisits, #

(select one)   If **YES...**

How many times total?   How many times were for...   How many times were for chest crisis?

NumberHospitalVisits, #   NumHospVisitsPain, #   NumHospVisitsACS, #

YesNoS
1 = Yes
0 = No

Any **emergency room / urgent care** visits not resulting in hospitalization?

EDVisits, #

(select one)   If **YES...**

How many times total?   How many times were for pain?   How many times were for chest crisis?

NumberEDVisits, #   NumEDVisitsPain, #   NumEDVisitsACS, #

In the past 30 days...

How many days did you miss from school or work due to physical or mental health?

DaysMissSchoolWork, #   # of days

How many days were you sick in bed or too ill to do daily activities?

DaysSick, #   # of days

How many days did you need someone to care for you due to physical or mental health?

DaysCare, #   # of days

If you work outside of the home or go to school, please answer the following questions:
In the past 30 days, has your health interfered with...

Your daily routine at work or school?   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Routine, #

Your ability to concentrate at work or school?   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Concentrate, #

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

MAGIC PedsQL Parent Report for Toddlers (age 4):

Toddler...(0/3) | PARENTP...(0/9) | PARENTP...(0/11) | -- Select to Jump --

Title: Visit at which survey was completed

At which visit this survey was completed? (select one) — **Visit, #**

Date on which this survey was completed: — **VisitDay, #**

Was this survey administered to the parent? — **SurveyParent, #**

Visit
0 = Time 0 - Prior to 1st study drug infusion
1 = Time 1 - After last dose of study drug
2 = Time 2 - Telephone follow-up
3 = Time 3 - Follow-up visit

YesNoS
1 = Yes
0 = No

Toddler...(0/3) | PARENTP...(0/9) | PARENTP...(0/11) | -- Select to Jump --

Title: Pain and Hurt

Subtitle: Sickle Cell Disease Module

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has been for your child. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Hurting a lot
PRHurtALot, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Hurting all over his/her body
PRHurtAllOver, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Hurting in his/her arms
PRHurtArms, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Hurting in his/her legs
PRHurtLegs, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Hurting in his/her stomach
PRHurtStomach, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Hurting in his/her chest
PRHurtChest, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Hurting in his/her back
PRHurtBack, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Having pain everyday
PRPainEveryday, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

Having so much pain that he/she has to take medicine
PRPainMedicine, # — Never / Almost never / Sometimes / Often / Almost always / Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄   PARENTP...(0/9)   **PARENTP...(0/11)**   PARENTW...(0/7)   ►   -- Select to Jump -- ▼

Title: Pain Impact

Subtitle: Sickle Cell Disease Module

How much of a problem has your child had with...

It is hard for him/her to do things because he/she might get pain

PRMightGetPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Missing school when he/she has pain

PRMissSchoolPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Wanting to be alone when he/she has pain

PRAlonePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to run when he/she has pain

PRRunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to have fun when having pain

PRFunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not

Having trouble moving around when he/she has pain

PRMovePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not

It is hard for him/her to stay standing when he/she has pain

PRStandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to take care of himself/herself when he/she has pain

PRTakeCarePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to do what others can do because he/she might get pain

PROtherMightGetPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Waking up at night when he/she has pain

PRUpAtNightPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Getting tired when he/she has pain

PRTiredPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

PARENTP...(0/11)   PARENTW....(0/7)   PARENTE...(0/3)   -- Select to Jump --

Title: Worry

Subtitle: Sickle Cell Disease Module

How much of a problem has your child had with...

Worrying that he/she will have pain

PRWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying that other people will not know what to do if he/she has pain

PRPeopleWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying when he/she is away from home

PRWorryAwayHome, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying he/she might have to go to the emergency room

PRWorryEmergency, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying he/she might have to stay overnight in the hospital

PRWorryHospital, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying he/she might have a stroke

PRWorryStroke, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying he/she might have a chest crisis

PRWorryChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

PARENTW...(0/7)   PARENTE...(0/3)   PARENTS...(0/11)   -- Select to Jump --

Title: Emotions

Subtitle: Sickle Cell Disease Module

How much of a problem has your child had with...

Getting scared about having needle sticks

PRScaredNeedles, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling mad about having sickle cell disease

PRMadDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling mad when he/she has pain

PRMadPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTE...(0/3) **PARENTS...(0/11)** PARENTC...(0/6) ► -- Select to Jump -- ▼

Title: My child's disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module

How much of a problem has your child had with...

Having headaches

PRHeadaches, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Getting yellow eyes when he/she is sick

PRYellowEyes, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to manage his/her pain

PRManagePain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to control his/her pain

PRControlPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Not liking how he/she feels after taking medicine

PRFeelsMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not a...

Not like the way his/her medicine tastes

PRTastesMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not a...

Medicine making him/her sleepy

PRSleepyMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying about whether his/her medicine is working

PRWorkingMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying about whether his/her treatments are working

PRWorkingTreatments, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Medicine not making him/her feel better

PRNotFeelBetterMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Other kids make him/her feel different because how he/she looks

PRFeelsDifferent, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTS...(0/11)   **PARENTC...(0/6)**   PARENTG...(0/6)   ►   -- Select to Jump --

Title: Communication

Subtitle: Sickle Cell Disease Module

How much of a problem has your child had with...

It is hard for him/her to tell others when he/she is in pain

PRTellOtherPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for him/her to tell the doctors and nurses how he/she feels

PRTellDocsPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for him/her to ask the doctors and nurses questions

PRAskQuestions, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for him/her when other people do not understand about his/her sickle cell disease

PRNotUnderstandDisease, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for him/her when others do not understand how much pain he/she feels

PRNotUnderstandPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for him/her to tell others that he/she has sickle cell disease

PRTellOthersDisease, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

---

◄ PARENTC...(0/6)   **PARENTG...(0/6)**   PARENTS...(0/6)   ►   -- Select to Jump --

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has... There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for your child...

Feeling tired

PRFeelTired, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Feeling physically weak (not strong)

PRFeelPhysicalWeak, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Feeling too tired to do things that he/she likes to do

PRFeelTiredForLikes, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Feeling too tired to spend time with his/her friends

PRFeelTiredFriends, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Trouble finishing things

PRTroubleFinish, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Trouble starting things

PRTroubleStart, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTG...(0/6)   **PARENTS...(0/6)**   PARENTC...(0/6)   ►   -- Select to Jump -- ▼

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale

How much of a problem has this been for your child...

Sleeping a lot

PRSleepALot, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty sleeping through the night

PRDifficultSleep, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling tired when he/she wakes up in the morning

PRFeelTiredMorning, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Resting a lot

PRRestALot, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Taking a lot of naps

PRTakingNaps, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Spending a lot of time in bed

PRTimeInBed, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

---

◄ PARENTS...(0/6)   **PARENTC...(0/6)**   PARENTP...(0/8)   ►   -- Select to Jump -- ▼

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale

How much of a problem has this been for your child...

Difficulty keeping his/her attention on things

PRAttention, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty remembering what people tell him/her

PRRememberTold, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty remembering what he/she just heard

PRRememberHeard, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty thinking quickly

PRThinkQuick, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble remembering what he/she was just thinking

PRRememberThink, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble remembering more than one thing at a time

PRRememberMoreOne, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ | PARENTC...(0/6) | **PARENTP...(0/8)** | PARENTE...(0/5) | ► | -- Select to Jump --

Title: Physical Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has been for your child. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Walking

PRWalking, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Running

PRRunning, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Participating in active play or exercise

PRPlayOrExercise, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Lifting something heavy

PRLiftHeavy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Bathing

PRBathing, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Helping to pick up his/her toys

PRPickUpToys, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having hurts or aches

PRHurtsOrAches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Low energy level

PRLowEnergy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ | PARENTP...(0/8) | **PARENTE...(0/5)** | PARENTS...(0/5) | ► | -- Select to Jump --

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version

How much of a problem has your child had with...

Feeling afraid or scared

PRFeelAfraid, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling sad or blue

PRFeelSad, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling angry

PRFeelAngry, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble sleeping

PRTroubleSleep, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying

PRWorrying, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ PARENTE...(0/5) **PARENTS...(0/5)** PARENTS...(0/3) ► -- Select to Jump -- ▼

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version

How much of a problem has your child had with...

Playing with other children

PRPlayWithChild, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Other kids not wanting to play with him/her

PRNoKidsWantToPlay, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Getting teased by other children

PRGetTeased, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Not able to do things that other children his/her age can do

PRNotAble, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Keeping up when playing with other children

PRKeepingUpWithOthers, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

---

◄ PARENTE...(0/5) PARENTS...(0/5) **PARENTS...(0/3)** ► -- Select to Jump -- ▼

Title: School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version

How much of a problem has your child had with...

Doing the same school activities as peers

PRSameActivities, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Missing school/daycare because of not feeling well

PRMissSchoolNotWell, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Missing school/daycare to go to the doctor or hospital

PRMissSchoolDoctor, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

MAGIC PedsQL Parent and Young Child Report (age 5-7):

Visit (0/5) | PainAnd...(0/9) | PainImp...(0/11) | ► | -- Select to Jump --

Title: Visit at which survey was completed

Please indicate at which visit this survey was completed? — Visit, #

Visit
0 = Time 0 - Prior to 1st study drug infusion
1 = Time 1 - After last dose of study drug
2 = Time 2 - Telephone follow-up
3 = Time 3 - Follow-up visit

Was this survey administered to the young child? — SurveyChild, #

Date on which young child survey was completed: — VisitDayChild, #

Was this survey administered to the parent? — SurveyParent, #

Date on which parent survey was completed: — VisitDayParent, #

YesNoS
1 = Yes
0 = No

Visit (0/4) | **PainAnd...(0/9)** | PainImp...(0/11) | ► | -- Select to Jump --

Title: About my pain and hurt

Subtitle: Sickle Cell Disease Module: Young Child Report

Instructions: for Interviewer: I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these might be for you.
Smiling face = Not at all (0)
Middle face = Sometimes (2)
Frowning face = A lot (4)

How much of a problem has this been for you...

Do you hurt a lot

HurtALot, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you hurt all over your body

HurtAllOver, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you hurt in your arms

HurtArms, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you hurt in your legs

HurtLegs, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you hurt in your stomach

HurtStomach, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you hurt in your chest

HurtChest, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you hurt in your back

HurtBack, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you have pain everyday

PainEveryday, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you have pain so much you need medicine

PainMedicine, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

PainAnd...(0/9)   **PainImp...(0/11)**   Worry (0/5)   ► -- Select to Jump --

Title: About my pain impact

Subtitle: Sickle Cell Disease Module: Young Child Report

How much of a problem has this been for you...

Is it hard for you to do things because of pain

MightGetPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you miss school when you have pain

MissSchoolPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you want to be alone when you have pain

AlonePain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to run when you have pain

RunPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to have fun when you have pain

FunPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you have trouble moving when you have pain

MovePain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to stay standing when you have pain

StandPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to take care of yourself when you have pain

TakeCarePain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to do what others can do because you might get pain

OtherMightGetPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you wake up at night when you have pain

UpAtNightPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you get tired when you have pain

TiredPain, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

◀ PainImp...(0/11) **Worry (0/5)** Emotions (0/3) ▶ -- Select to Jump -- ▼

Title: About me worrying

Subtitle: Sickle Cell Disease Module: Young Child Report

How much of a problem has this been for you...

Do you worry that you will have pain

WorryPain, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

Do you worry that other people with not know what to do if you have pain

PeopleWorryPain, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

Do you worry when you are away from home

WorryAwayHome, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

Do you worry you might have to go to the emergency room

WorryEmergency, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

Do you worry you might have to stay overnight in the hospital

WorryHospital, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

◀ Worry (0/5) **Emotions (0/3)** Symptom...(0/11) ▶ -- Select to Jump -- ▼

Title: About my emotions

Subtitle: Sickle Cell Disease Module: Young Child Report

How much of a problem has this been for you...

Do needle sticks scare you

ScaredNeedles, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

Do you feel mad you have sickle cell disease

MadDisease, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

Do you feel mad when you have pain

MadPain, # ◯ Not at all ◯ Sometimes ◯ A lot ◯ Not answered

Emotions (0/3) | **Symptom...(0/11)** | Communi...(0/6) | ► | -- Select to Jump --

Title: About my disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module: Young Child Report

How much of a problem has this been for you...

Do you have headaches

Headaches, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you get yellow eyes when you are sick

YellowEyes, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to manage your pain

ManagePain, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to control your pain

ControlPain, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you not like how you feel after you take your medicine

FeelsMedicine, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you not like the way your medicine tastes

TastesMedicine, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Does your medicine make you sleepy

SleepyMedicine, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you worry about whether your medicine is working

WorkingMedicine, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you worry about whether your treatments are working

WorkingTreatments, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Does your medicine not make you feel better

NotFeelBetterMedicine, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do other kids make you feel different because of how you look

FeelsDifferent, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

◄ Symptom...(0/11) **Communi...(0/6)** General...(0/6) ► -- Select to Jump -- ▼

Title: About communication

Subtitle: Sickle Cell Disease Module: Young Child Report

How much of a problem has this been for you...

Is it hard for you to tell others when you are in pain

TellOtherPain, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to tell the doctors and nurses how you feel

TellDocsPain, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to ask the doctors and nurses questions

AskQuestions, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you when other people do not understand about your sickle cell disease

NotUnderstandDisease, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you when others do not understand how much pain you are feeling

NotUnderstandPain, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to tell others that you have sickle cell disease

TellOthersDisease, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

◄ Communi...(0/6) **General...(0/6)** SleepFa...(0/6) ► -- Select to Jump -- ▼

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale: Young Child Report

Instructions: for Interviewer: I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these might be for you.
Smiling face = Not at all (0)
Middle face = Sometimes (2)
Frowning face = A lot (4)

How much of a problem has this been for you...

FeelTired, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

FeelPhysicalWeak, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

FeelTiredForLikes, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

FeelTiredFriends, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

TroubleFinish, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

TroubleStart, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

◀ General...(0/6) **SleepFa...(0/6)** Cogniti...(0/6) ▶ -- Select to Jump -- ▾

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale: Young Child Report

How much of a problem has this been for you...

Do you sleep a lot

SleepALot, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to sleep through the night

DifficultSleep, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you feel tired when you wake up in the morning

FeelTiredMorning, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you rest a lot

RestALot, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you take a lot of naps

TakingNaps, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you spend a lot of time in bed

TimeInBed, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

◀ SleepFa...(0/6) **Cogniti...(0/6)** Physica...(0/9) ▶ -- Select to Jump -- ▾

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale: Young Child Report

How much of a problem has this been for you...

Is it hard for you to keep your attention on things

Attention, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to remember what people tell you

RememberTold, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to remember what you just heard

RememberHeard, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to think quickly

ThinkQuick, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you have trouble remembering what you were just thinking

RememberThink, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you have trouble remembering more than one thing at a time

RememberMoreOne, # ○ Not at all ○ Sometimes ○ A lot ○ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

Cogniti...(0/6) **Physica...(0/9)** Emotion...(0/5) ► -- Select to Jump --

Title: Physical Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Child Report

Instructions: for Interviewer: I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these might be for you.
Smiling face = Not at all (0)
Middle face = Sometimes (2)
Frowning face = A lot (4)

How much of a problem has this been for you...

Is it hard for you to walk

Walking, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to run

Running, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to play sports or exercise

PlayOrExercise, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to pick up big things

LiftHeavy, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to take a bath or shower

Bathing, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to do chores (like pick up your toys)

PickUpToys, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you have hurts or aches

HurtsOrAches, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Specify where you have hurts or aches (if applicable)   **HurtsOrAchesSpecify, $23**

Do you ever feel too tired to play

LowEnergy, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

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Physica...(0/9) **Emotion...(0/5)** SocialF...(0/5) ► -- Select to Jump --

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Child Report

How much of a problem has this been for you...

Do you feel scared

FeelAfraid, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you feel sad

FeelSad, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you feel mad

FeelAngry, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you have trouble sleeping

TroubleSleep, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you worry about what will happen to you

Worrying, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

◄ Emotion...(0/5) **SocialF...(0/5)** SchoolF...(0/5) ► -- Select to Jump -- ▼

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Child Report

How much of a problem has this been for you...

Is it hard for you to get along with other kids

PlayWithChild, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do other kids say they do not want to play with you

NoKidsWantToPlay, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do other kids tease you

GetTeased, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Can other kids do things that you cannot do

NotAble, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard for you to keep up when you play with other kids

KeepingUpWithOthers, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

◄ SocialF...(0/5) **SchoolF...(0/5)** PARENTP...(0/9) ► -- Select to Jump -- ▼

Title: School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Child Report

How much of a problem has this been for you...

Is it hard for you to pay attention in school

PayAttention, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you forget things

ForgetThings, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Is it hard to keep up with schoolwork

KeepUpWithSchool, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you miss school because of not feeling good

MissSchoolNotWell, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

Do you miss school because you have to go to the doctor's or hospital

MissSchoolDoctor, #   ○ Not at all ○ Sometimes ○ A lot ○ Not answered

YCScale
0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered

| SchoolF...(0/5) | **PARENTP...**(0/9) | PARENTP...(0/11) | ► | -- Select to Jump -- ▼ |

Title: Pain and Hurt

Subtitle: Sickle Cell Disease Module: Parent Report for Young Children

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has been for your child. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Hurting a lot

PRHurtALot, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting all over his/her body

PRHurtAllOver, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her arms

PRHurtArms, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her legs

PRHurtLegs, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her stomach

PRHurtStomach, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her chest

PRHurtChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her back

PRHurtBack, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having pain everyday

PRPainEveryday, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having so much pain that he/she has to take medicine

PRPainMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

PARENTP...(0/9)   **PARENTP...(0/11)**   PARENTW...(0/7)   ► -- Select to Jump -- ▼

Title: Pain Impact

Subtitle: Sickle Cell Disease Module: Parent Report for Young Children

How much of a problem has your child had with...

It is hard for him/her to do things because he/she might get pain

PRMightGetPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Missing school when he/she has pain

PRMissSchoolPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Wanting to be alone when he/she has pain

PRAlonePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to run when he/she has pain

PRRunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to have fun when having pain

PRFunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Having trouble moving around when he/she has pain

PRMovePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to stay standing when he/she has pain

PRStandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to take care of himself/herself when he/she has pain

PRTakeCarePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to do what others can do because he/she might get pain

PROtherMightGetPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Waking up at night when he/she has pain

PRUpAtNightPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Getting tired when he/she has pain

PRTiredPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

PARENTP...(0/11)   PARENTW...(0/7)   PARENTE...(0/3)   ► -- Select to Jump --

Title: Worry

Subtitle: Sickle Cell Disease Module: Parent Report for Young Children

How much of a problem has your child had with...

Worrying that he/she will have pain

PRWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying that other people will not know what to do if he/she has pain

PRPeopleWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying when he/she is away from home

PRWorryAwayHome, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have to go to the emergency room

PRWorryEmergency, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have to stay overnight in the hospital

PRWorryHospital, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have a stroke

PRWorryStroke, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have a chest crisis

PRWorryChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

PARENTW...(0/7)   PARENTE...(0/3)   PARENTS...(0/11)   ► -- Select to Jump --

Title: Emotions

Subtitle: Sickle Cell Disease Module: Parent Report for Young Children

How much of a problem has your child had with...

Getting scared about having needle sticks

PRScaredNeedles, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Feeling mad about having sickle cell disease

PRMadDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Feeling mad when he/she has pain

PRMadPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

PARENTE...(0/3)   **PARENTS...(0/11)**   PARENTC...(0/6)   ▶   -- Select to Jump --   ▼

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: My child's disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module: Parent Report for Young Children

How much of a problem has your child had with...

Having headaches

PRHeadaches, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Getting yellow eyes when he/she is sick

PRYellowEyes, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for him/her to manage his/her pain

PRManagePain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for him/her to control his/her pain

PRControlPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Not liking how he/she feels after taking medicine

PRFeelsMedicine, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Not liking the way his/her medicine tastes

PRTastesMedicine, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Medicine making him/her sleepy

PRSleepyMedicine, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying about whether his/her medicine is working

PRWorkingMedicine, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying about whether his/her treatments are working

PRWorkingTreatments, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Medicine not making him/her feel better

PRNotFeelBetterMedicine, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Other kids make him/her feel different because how he/she looks

PRFeelsDifferent, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

◄ **PARENTS...(0/11)** | **PARENTC...(0/6)** | **PARENTG...(0/6)** ► | -- Select to Jump -- ▼

Title: Communication

Subtitle: Sickle Cell Disease Module: Parent Report for Young Children

How much of a problem has your child had with...

It is hard for him/her to tell others when he/she is in pain

PRTellOtherPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to tell the doctors and nurses how he/she feels

PRTellDocsPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to ask the doctors and nurses questions

PRAskQuestions, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her when other people do not understand about his/her sickle cell disease

PRNotUnderstandDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her when other people do not understand how much pain he/she feels

PRNotUnderstandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to tell others that he/she has sickle cell disease

PRTellOthersDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ **PARENTC...(0/6)** | **PARENTG...(0/6)** | **PARENTS...(0/6)** ► | -- Select to Jump -- ▼

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Young Children

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has be... There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for your child...

Feeling tired

PRFeelTired, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling physically weak (not strong)

PRFeelPhysicalWeak, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling too tired to do things that he/she likes to do

PRFeelTiredForLikes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling too tired to spend time with his/her friends

PRFeelTiredFriends, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble finishing things

PRTroubleFinish, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble starting things

PRTroubleStart, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ PARENTG...(0/6) **PARENTS...**(0/6) PARENTC...(0/6) ► -- Select to Jump --

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Young Children

How much of a problem has this been for your child...

Sleeping a lot

PRSleepALot, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty sleeping through the night

PRDifficultSleep, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling tired when he/she wakes up in the morning

PRFeelTiredMorning, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Resting a lot

PRRestALot, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Taking a lot of naps

PRTakingNaps, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Spending a lot of time in bed

PRTimeInBed, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ PARENTS...(0/6) **PARENTC...**(0/6) PARENTP...(0/8) ► -- Select to Jump --

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Young Children

How much of a problem has this been for your child...

Difficulty keeping his/her attention on things

PRAttention, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty remembering what people tell him/her

PRRememberTold, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty remembering what he/she just heard

PRRememberHeard, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Difficulty thinking quickly

PRThinkQuick, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble remembering what he/she was just thinking

PRRememberThink, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble remembering more than one thing at a time

PRRememberMoreOne, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ **PARENTC...**(0/6)   **PARENTP...**(0/8)   **PARENTE...**(0/5) ►   -- Select to Jump -- ▼

Title: Physical Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Young Children

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has been for your child. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Walking more than one block

PRWalking, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Running

PRRunning, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Participating in sports activity or exercise

PRPlayOrExercise, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Lifting something heavy

PRLiftHeavy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Taking a bath or shower by himself/herself

PRBathing, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Doing chores, like picking up his or her toys

PRPickUpToys, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having hurts or aches

PRHurtsOrAches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Low energy level

PRLowEnergy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ **PARENTP...**(0/8)   **PARENTE...**(0/5)   **PARENTS...**(0/5) ►   -- Select to Jump -- ▼

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Young Children

How much of a problem has your child had with...

Feeling afraid or scared

PRFeelAfraid, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling sad or blue

PRFeelSad, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling angry

PRFeelAngry, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble sleeping

PRTroubleSleep, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying about what will happen to him/her

PRWorrying, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ PARENTE...(0/5) | **PARENTS...**(0/5) | PARENTS...(0/5) ► | -- Select to Jump -- ▼

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Young Children

How much of a problem has your child had with...

Getting along with other children

PRPlayWithChild, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Other kids not wanting to be his/her friend

PRNoKidsWantToPlay, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Getting teased by other children

PRGetTeased, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Not able to do things that other children his/her age can do

PRNotAble, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Keeping up when playing with other children

PRKeepingUpWithOthers, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTE...(0/5) | PARENTS...(0/5) | **PARENTS...**(0/5) ► | -- Select to Jump -- ▼

Title: School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Young Children

How much of a problem has your child had with...

Paying attention in class

PRPayAttention, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Forgetting things

PRForgetThings, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Keeping up with school activities

PRKeepUpWithSchool, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Missing school because of not feeling well

PRMissSchoolNotWell, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

Missing school to go to the doctor or hospital

PRMissSchoolDoctor, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always | ○ Not answered

MAGiC PedsQL Child and Parent QOL Survey Dates:

◄ **SurveyD...(0/5)** ► -- Select to Jump -- ▼

Title: This form is to be completed for subjects enrolled prior to December 19, 2011.

Please indicate at which visit the child and/or parent survey dates are referring to?
(select one) | Visit, # | ▼

Visit
0 = Time 0 - Prior to 1st study drug infusion
1 = Time 1 - After last dose of study drug
2 = Time 2 - Telephone follow-up
3 = Time 3 - Follow-up visit

Was the survey administered to the child? | SurveyChild, #

Date on which child survey was completed: | VisitDayChild, # | 🗓

YesNoS
1 = Yes
0 = No

Was the survey administered to the parent? | SurveyParent, #

Date on which parent survey was completed: | VisitDayParent, # | 🗓

MAGiC PedsQL Parent and Child Report (ages 8-12):

| ChildVi...(0/5) | PainAnd...(0/9) | PainImp...(0/11) | ▶ | -- Select to Jump -- ▼ |

Title: Visit at which survey was completed

Please indicate at which visit this survey was completed? (select

Visit, #

Visit
0 = Time 0 - Prior to 1st study drug infusion
1 = Time 1 - After last dose of study drug
2 = Time 2 - Telephone follow-up
3 = Time 3 - Follow-up visit

YesNoS
1 = Yes
0 = No

Was this survey administered to the child?

SurveyChild, #

Date on which child survey was completed:

VisitDayChild, #

Was this survey administered to the parent?

SurveyParent, #

Date on which parent survey was completed:

VisitDayParent, #

| ChildVi...(0/4) | PainAnd...(0/9) | PainImp...(0/11) | ▶ | -- Select to Jump -- ▼ |

Title: About my pain and hurt

Subtitle: Sickle Cell Disease Module: Child Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one has been for you. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

I hurt a lot

HurtALot, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt all over my body

HurtAllOver, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my arms

HurtArms, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my legs

HurtLegs, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

I hurt in my stomach

HurtStomach, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my chest

HurtChest, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my back

HurtBack, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have pain everyday

PainEveryday, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have pain so much that I need medicine

PainMedicine, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ **PainAnd...**(0/9) **PainImp...**(0/11) **Worry (0/7)** ► -- Select to Jump -- ▼

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: About my pain impact

Subtitle: Sickle Cell Disease Module: Child Report

How much of a problem has this been for you...

It is hard for me to do things because I might get pain

MightGetPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I miss school when I have pain

MissSchoolPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I want to be alone when I have pain

AlonePain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to run when I have pain

RunPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard to have fun when I have pain

FunPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble moving when I have pain

MovePain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard to stay standing when I have pain

StandPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to take care of myself when I have pain

TakeCarePain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to do what others can do because I might get pain

OtherMightGetPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I wake up at night when I have pain

UpAtNightPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I get tired when I have pain

TiredPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

PainImp...(0/11) | **Worry (0/7)** | Emotions (0/3) | -- Select to Jump --

Title: About me worrying

Subtitle: Sickle Cell Disease Module: Child Report

How much of a problem has this been for you...

I worry that I will have pain

WorryPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry that other people will not know what to do if I have pain

PeopleWorryPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry when I am away from home

WorryAwayHome, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have to go to the emergency room

WorryEmergency, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have to stay overnight in the hospital

WorryHospital, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have a stroke

WorryStroke, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have a chest crisis

WorryChest, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

---

Worry (0/7) | **Emotions (0/3)** | Symptom...(0/12) | -- Select to Jump --

Title: About my emotions

Subtitle: Sickle Cell Disease Module: Child Report

How much of a problem has this been for you...

Needle sticks scare me

ScaredNeedles, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel mad I have sickle cell disease

MadDisease, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel mad when I have pain

MadPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ Emotions (0/3) **Symptom...(0/12)** Communi...(0/6) ► -- Select to Jump -- ▼

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: About my disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module: Child Report

How much of a problem has this been for you...

I have headaches

Headaches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I get yellow eyes when I am sick

YellowEyes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to manage my pain

ManagePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to control my pain

ControlPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to remember to take my medicine

TakeMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I do not like how I feel after I take my medicine

FeelsMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I do not like the way my medicine tastes

TastesMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

My medicine makes me sleepy

SleepyMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry about whether my medicine is working

WorkingMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry about whether my treatments are working

WorkingTreatments, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

My medicine does not make me feel better

NotFeelBetterMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Other kids make me feel different because of how I look

FeelsDifferent, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ | Symptom...(0/12) | **Communi...(0/6)** | General...(0/6) | ► | -- Select to Jump -- ▾

Title: About communication

Subtitle: Sickle Cell Disease Module: Child Report

How much of a problem has this been for you...

It is hard for me to tell others when I am in pain

TellOtherPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to tell the doctors and nurses how I feel

TellDocsPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to ask the doctors and nurses questions

AskQuestions, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me when others do not understand about my sickle cell disease

NotUnderstandDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me when others do not understand how much pain I feel

NotUnderstandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to tell others that I have sickle cell disease

TellOthersDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

◄ | Communi...(0/6) | **General...(0/6)** | SleepFa...(0/6) | ► | -- Select to Jump -- ▾

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale: Child Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one h
There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

I feel tired

FeelTired, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel physically weak (not strong)

FeelPhysicalWeak, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel too tired to do things that I like to do

FeelTiredForLikes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel too tired to spend time with my friends

FeelTiredFriends, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble finishing things

TroubleFinish, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble starting things

TroubleStart, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

MAGiC PUD Annotated eCRF, Version 1.0

General…(0/6)   **SleepFa…**(0/6)   Cogniti…(0/6)   ► -- Select to Jump --

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale: Child Report

How much of a problem has this been for you…

I sleep a lot

SleepALot, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to sleep through the night

DifficultSleep, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I feel tired when I wake up in the morning

FeelTiredMorning, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I rest a lot

RestALot, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I take a lot of naps

TakingNaps, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I spend a lot of time in bed

TimeInBed, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

---

SleepFa…(0/6)   **Cogniti…**(0/6)   Physica…(0/8)   ► -- Select to Jump --

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale: Child Report

How much of a problem has this been for you…

It is hard for me to keep my attention on things

Attention, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to remember what people tell me

RememberTold, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to remember what I just heard

RememberHeard, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to think quickly

ThinkQuick, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I have trouble remembering what I was just thinking

RememberThink, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I have trouble remembering more than one thing at a time

RememberMoreOne, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

MAGiC PUD Annotated eCRF, Version 1.0

Cogniti...(0/6)   **Physica...(0/8)**   Emotion...(0/5)   ►   -- Select to Jump --

Title: Physical Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Child Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one has been for you. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

It is hard for me to walk more than one block

Walking, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to run

Running, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to do sports activity or exercise

PlayOrExercise, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to lift something heavy

LiftHeavy, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to take a bath or shower by myself

Bathing, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to do chores around the house

PickUpToys, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I hurt or ache

HurtsOrAches, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I have low energy

LowEnergy, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Physica...(0/8)   **Emotion...(0/5)**   SocialF...(0/5)   ►   -- Select to Jump --

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Child Report

How much of a problem has this been for you...

I feel afraid or scared

FeelAfraid, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I feel sad or blue

FeelSad, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I feel angry

FeelAngry, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I have trouble sleeping

TroubleSleep, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I worry about what will happen to me

Worrying, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

◄ Emotion...(0/5) | **SocialF...(0/5)** | SchoolF...(0/5) | ► | -- Select to Jump -- ▾

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Child Report

How much of a problem has this been for you...

I have trouble getting along with other kids

PlayWithChild, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Other kids do not want to be my friend

NoKidsWantToPlay, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Other kids tease me

GetTeased, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I cannot do things that other kids my age can do

NotAble, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard to keep up when I play with other kids

KeepingUpWithOthers, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

---

◄ SocialF...(0/5) | **SchoolF...(0/5)** | PARENTP...(0/9) | ► | -- Select to Jump -- ▾

Title: School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Child Report

How much of a problem has this been for you...

It is hard to pay attention in class

PayAttention, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I forget things

ForgetThings, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I have trouble keeping up with my schoolwork

KeepUpWithSchool, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I miss school because of not feeling well

MissSchoolNotWell, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I miss school to go to the doctor or hospital

MissSchoolDoctor, #

○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ SchoolF...(0/5) **PARENTP...(0/9)** PARENTP...(0/11) ► -- Select to Jump --

Title: Pain and Hurt

Subtitle: Sickle Cell Disease Module: Parent Report for Children

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has been for your child. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Hurting a lot

PRHurtALot, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting all over his/her body

PRHurtAllOver, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her arms

PRHurtArms, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her legs

PRHurtLegs, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her stomach

PRHurtStomach, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her chest

PRHurtChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her back

PRHurtBack, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having pain everyday

PRPainEveryday, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having so much pain that he/she has to take medicine

PRPainMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ **PARENTP...**(0/9)   **PARENTP...**(0/11)   **PARENTW...**(0/7)   ►   -- Select to Jump --   ▼

Title: Pain Impact

Subtitle: Sickle Cell Disease Module: Parent Report for Children

How much of a problem has your child had with...

It is hard for him/her to do things because he/she might get pain

PRMightGetPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Missing school when he/she has pain

PRMissSchoolPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Wanting to be alone when he/she has pain

PRAlonePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to run when he/she has pain

PRRunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to have fun when having pain

PRFunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Having trouble moving around when he/she has pain

PRMovePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to stay standing when he/she has pain

PRStandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to take care of himself/herself when he/she has pain

PRTakeCarePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to do what others can do because he/she might get pain

PROtherMightGetPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Waking up at night when he/she has pain

PRUpAtNightPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Getting tired when he/she has pain

PRTiredPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

| PARENTP...(0/11) | **PARENTW...(0/7)** | PARENTE...(0/3) | ▶ | -- Select to Jump -- ▾ |

Title: Worry

Subtitle: Sickle Cell Disease Module: Parent Report for Children

How much of a problem has your child had with...

Worrying that he/she will have pain

PRWorryPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying that other people will not know what to do if he/she has pain

PRPeopleWorryPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying when he/she is away from home

PRWorryAwayHome, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying he/she might have to go to the emergency room

PRWorryEmergency, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying he/she might have to stay overnight in the hospital

PRWorryHospital, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying he/she might have a stroke

PRWorryStroke, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Worrying he/she might have a chest crisis

PRWorryChest, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

| PARENTW...(0/7) | **PARENTE...(0/3)** | PARENTS...(0/12) | ▶ | -- Select to Jump -- ▾ |

Title: Emotions

Subtitle: Sickle Cell Disease Module: Parent Report for Children

How much of a problem has your child had with...

Getting scared about having needle sticks

PRScaredNeedles, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Feeling mad about having sickle cell disease

PRMadDisease, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Feeling mad when he/she has pain

PRMadPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

PARENTE...(0/3) **PARENTS...(0/12)** PARENTC...(0/6) ▶ -- Select to Jump -- ▾

Title: My child's disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module: Parent Report for Children

How much of a problem has your child had with...

Having headaches

PRHeadaches, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Getting yellow eyes when he/she is sick

PRYellowEyes, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to manage his/her pain

PRManagePain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to control his/her pain

PRControlPain, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to remember to take his/her medicine

PRTakeMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Not liking how he/she feels after taking medicine

PRFeelsMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Not like the way his/her medicine tastes

PRTastesMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Medicine making him/her sleepy

PRSleepyMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying about whether his/her medicine is working

PRWorkingMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying about whether his/her treatments are working

PRWorkingTreatments, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Medicine not making him/her feel better

PRNotFeelBetterMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Other kids make him/her feel different because how he/she looks

PRFeelsDifferent, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

PARENTS...(0/12)   **PARENTC...(0/6)**   PARENTG...(0/6)   -- Select to Jump --

Title: Communication

Subtitle: Sickle Cell Disease Module: Parent Report for Children

How much of a problem has your child had with...

It is hard for him/her to tell others when he/she is in pain

PRTellOtherPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to tell the doctors and nurses how he/she feels

PRTellDocsPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to ask the doctors and nurses questions

PRAskQuestions, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her when other people do not understand about his/her sickle cell disease

PRNotUnderstandDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her when others do not understand how much pain he/she feels

PRNotUnderstandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to tell others that he/she has sickle cell disease

PRTellOthersDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

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PARENTC...(0/6)   **PARENTG...(0/6)**   PARENTS...(0/6)   -- Select to Jump --

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Children

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has been There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for your child...

Feeling tired

PRFeelTired, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling physically weak (not strong)

PRFeelPhysicalWeak, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling too tired to do things that he/she likes to do

PRFeelTiredForLikes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling too tired to spend time with his/her friends

PRFeelTiredFriends, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble finishing things

PRTroubleFinish, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble starting things

PRTroubleStart, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTG...(0/6)　PARENTS...(0/6)　PARENTC...(0/6)　▶　-- Select to Jump --

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Children

How much of a problem has this been for your child...

Sleeping a lot

PRSleepALot, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Difficulty sleeping through the night

PRDifficultSleep, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Feeling tired when he/she wakes up in the morning

PRFeelTiredMorning, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Resting a lot

PRRestALot, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Taking a lot of naps

PRTakingNaps, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Spending a lot of time in bed

PRTimeInBed, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

◄ PARENTS...(0/6)　PARENTC...(0/6)　PARENTP...(0/8)　▶　-- Select to Jump --

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Children

How much of a problem has this been for your child...

Difficulty keeping his/her attention on things

PRAttention, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Difficulty remembering what people tell him/her

PRRememberTold, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Difficulty remembering what he/she just heard

PRRememberHeard, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Difficulty thinking quickly

PRThinkQuick, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Trouble remembering what he/she was just thinking

PRRememberThink, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

Trouble remembering more than one thing at a time

PRRememberMoreOne, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　　○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTC...(0/6)   **PARENTP...(0/8)**   PARENTE...(0/5)   ► -- Select to Jump -- ▾

Title: Physical Functioning

PARENTPhysicalFunction (0/8)

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Children

Instructions: On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem for each one has been for your child. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Walking more than one block

PRWalking, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Running

PRRunning, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Participating in sports activity or exercise

PRPlayOrExercise, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Lifting something heavy

PRLiftHeavy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Taking a bath or shower by himself/herself

PRBathing, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Doing chores around the house

PRPickUpToys, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having hurts or aches

PRHurtsOrAches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Low energy level

PRLowEnergy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ PARENTP...(0/8)   **PARENTE...(0/5)**   PARENTS...(0/5)   ► -- Select to Jump -- ▾

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Children

How much of a problem has your child had with...

Feeling afraid or scared

PRFeelAfraid, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling sad or blue

PRFeelSad, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling angry

PRFeelAngry, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble sleeping

PRTroubleSleep, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying about what will happen to him/her

PRWorrying, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ **PARENTE...**(0/5)　　**PARENTS...**(0/5)　　**PARENTS...**(0/5)　► | -- Select to Jump -- ▼

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Children

How much of a problem has your child had with...

Getting along with other children

PRPlayWithChild, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Other kids not wanting to be his/her friend

PRNoKidsWantToPlay, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Getting teased by other children

PRGetTeased, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Not able to do things that other children his/her age can do

PRNotAble, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Keeping up when playing with other children

PRKeepingUpWithOthers, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ **PARENTE...**(0/5)　　**PARENTS...**(0/5)　　**PARENTS...**(0/5)　► | -- Select to Jump -- ▼

Title: School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Children

How much of a problem has your child had with...

Paying attention in class

PRPayAttention, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Forgetting things

PRForgetThings, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Keeping up with schoolwork

PRKeepUpWithSchool, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Missing school because of not feeling well

PRMissSchoolNotWell, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Missing school to go to the doctor or hospital

PRMissSchoolDoctor, #

○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

MAGiC PedsQL Parent and Teen Report (ages 13-18):

TeenVis...(0/5) PainAnd...(0/9) PainImp...(0/11) ▶ -- Select to Jump --

Title: Visit at which survey was completed

Please indicate at which visit this survey was completed? (sele | Visit, # |

Visit
0 = Time 0 - Prior to 1st study drug infusion
1 = Time 1 - After last dose of study drug
2 = Time 2 - Telephone follow-up
3 = Time 3 - Follow-up visit

YesNoS
1 = Yes
0 = No

Was this survey administered to the teen? | SurveyChild, # | Date on which teen survey was completed: | VisitDayChild, # |

Was this survey administered to the parent? | SurveyParent, # | Date on which parent survey was completed: | VisitDayParent, # |

TeenVis...(0/4) **PainAnd...(0/9)** PainImp...(0/11) ▶ -- Select to Jump --

Title: About my pain and hurt

Subtitle: Sickle Cell Disease Module: Teen Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one has been for you. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

I hurt a lot

| HurtALot, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt all over my body

| HurtAllOver, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my arms

| HurtArms, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my legs

| HurtLegs, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my stomach

| HurtStomach, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my chest

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

| HurtChest, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my back

| HurtBack, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have pain everyday

| PainEveryday, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have so much pain that I need medicine

| PainMedicine, # | ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ **PainAnd...**(0/9) | **PainImp...**(0/11) | **Worry** (0/7) ► -- Select to Jump --

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: About my pain impact

Subtitle: Sickle Cell Disease Module: Teen Report

How much of a problem has this been for you...

Is it hard for me to do things because I might get pain

MightGetPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I miss school when I have pain

MissSchoolPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I want to be alone when I have pain

AlonePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to run when I have pain

RunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard to have fun when I have pain

FunPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble moving when I have pain

MovePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard to stay standing when I have pain

StandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to take care of myself when I have pain

TakeCarePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to do what others can do because I might get pain

OtherMightGetPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I wake up at night when I have pain

UpAtNightPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I get tired when I have pain

TiredPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ **PainImp...**(0/11) | **Worry** (0/7) | **Emotions** (0/3) ► | -- Select to Jump --

Title: About me worrying

Subtitle: Sickle Cell Disease Module: Teen Report

How much of a problem has this been for you...

I worry that I will have pain

WorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry that others will not know what to do if I have pain

PeopleWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry when I am away from home

WorryAwayHome, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have to go to the emergency room

WorryEmergency, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have to stay overnight in the hospital

WorryHospital, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have a stroke

WorryStroke, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry I might have a chest crisis

WorryChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ **Worry** (0/7) | **Emotions** (0/3) | **Symptom...**(0/12) ► | -- Select to Jump --

Title: About my emotions

Subtitle: Sickle Cell Disease Module: Teen Report

How much of a problem has this been for you...

Needle sticks scare me

ScaredNeedles, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel mad I have sickle cell disease

MadDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel mad when I have pain

MadPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Emotions (0/3)   **Symptom...(0/12)**   Communi...(0/6)   ▶   -- Select to Jump --

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: About my disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module: Teen Report

How much of a problem has this been for you...

I have headaches

Headaches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I get yellow eyes when I am sick

YellowEyes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to manage my pain

ManagePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to control my pain

ControlPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to remember to take my medicine

TakeMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I do not like how I feel after I take my medicine

FeelsMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I do not like the way my medicine tastes

TastesMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

My medicine makes me sleepy

SleepyMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry about whether my medicine is working

WorkingMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry about whether my treatments are working

WorkingTreatments, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

My medicine does not make me feel better

NotFeelBetterMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Other kids make me feel different because of how I look

FeelsDifferent, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Symptom...(0/12) | Communi...(0/6) | General...(0/6) | -- Select to Jump -- ▼

Title: About communication

Subtitle: Sickle Cell Disease Module: Teen Report

How much of a problem has this been for you...

It is hard for me to tell others when I am in pain

TellOtherPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to tell the doctors and nurses how I feel

TellDocsPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to ask the doctors and nurses questions

AskQuestions, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me when others do not understand about my sickle cell disease

NotUnderstandDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me when others do not understand how much pain I feel

NotUnderstandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to tell others that I have sickle cell disease

TellOthersDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

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Communi...(0/6) | General...(0/6) | SleepFa...(0/6) | -- Select to Jump -- ▼

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale: Teen Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one has [...] There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

I feel tired

FeelTired, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel physically weak (not strong)

FeelPhysicalWeak, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel too tired to do things that I like to do

FeelTiredForLikes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel too tired to spend time with my friends

FeelTiredFriends, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble finishing things

TroubleFinish, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble starting things

TroubleStart, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

General...(0/6) **SleepFa...(0/6)** Cogniti...(0/6) ► -- Select to Jump --

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale: Teen Report

How much of a problem has this been for you...

I sleep a lot

SleepALot, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to sleep through the night

DifficultSleep, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel tired when I wake up in the morning

FeelTiredMorning, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I rest a lot

RestALot, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I take a lot of naps

TakingNaps, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I spend a lot of time in bed

TimeInBed, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

SleepFa...(0/6) **Cogniti...(0/6)** Physica...(0/8) ► -- Select to Jump --

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale: Teen Report

How much of a problem has this been for you...

It is hard for me to keep my attention on things

Attention, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to remember what people tell me

RememberTold, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to remember what I just heard

RememberHeard, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to think quickly

ThinkQuick, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble remembering what I was just thinking

RememberThink, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble remembering more than one thing at a time

RememberMoreOne, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Cogniti...(0/6)   **Physica...(0/8)**   Emotion...(0/5)   ► -- Select to Jump --

Title: Physical Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Teen Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one has been for you. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

It is hard for me to walk more than one block

Walking, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to run

Running, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to do sports activity or exercise

PlayOrExercise, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to lift something heavy

LiftHeavy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to take a bath or shower by myself

Bathing, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to do chores around the house

PickUpToys, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt or ache

HurtsOrAches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have low energy

LowEnergy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Physica...(0/8)   **Emotion...(0/5)**   SocialF...(0/5)   ► -- Select to Jump --

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Teen Report

How much of a problem has this been for you...

I feel afraid or scared

FeelAfraid, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel sad or blue

FeelSad, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel angry

FeelAngry, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble sleeping

TroubleSleep, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry about what will happen to me

Worrying, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ Emotion...(0/5) | **SocialF...(0/5)** | SchoolF...(0/5) ► | -- Select to Jump -- ▼

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Teen Report

How much of a problem has this been for you...

I have trouble getting along with other teens

PlayWithChild, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Other teens do not want to be my friend

NoKidsWantToPlay, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Other teens tease me

GetTeased, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I cannot do things that other teens my age can do

NotAble, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard to keep up with my peers

KeepingUpWithOthers, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

◄ SocialF...(0/5) | **SchoolF...(0/5)** | PARENTP...(0/9) ► | -- Select to Jump -- ▼

Title: School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Teen Report

How much of a problem has this been for you...

It is hard to pay attention in class

PayAttention, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I forget things

ForgetThings, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I have trouble keeping up with my schoolwork

KeepUpWithSchool, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I miss school because of not feeling well

MissSchoolNotWell, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I miss school to go to the doctor or hospital

MissSchoolDoctor, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ SchoolF...(0/5) | **PARENTP...(0/9)** | PARENTP...(0/11) ► | -- Select to Jump -- ▼

Title: Pain and Hurt

Subtitle: Sickle Cell Disease Module: Parent Report for Teens

Instructions: On the following pages is a list of things that might be a problem for your teen. Please tell us how much of a problem for each one has been for your teen. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Hurting a lot

PRHurtALot, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting all over his/her body

PRHurtAllOver, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her arms

PRHurtArms, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her legs

PRHurtLegs, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her stomach

PRHurtStomach, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her chest

PRHurtChest, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Hurting in his/her back

PRHurtBack, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having pain everyday

PRPainEveryday, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having so much pain that he/she has to take medicine

PRPainMedicine, #

○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

PARENTP...(0/9) | **PARENTP...(0/11)** | PARENTW...(0/7) | ► | -- Select to Jump --

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: Pain Impact

Subtitle: Sickle Cell Disease Module: Parent Report for Teens

How much of a problem has your child had with...

It is hard for him/her to do things because him/her might get pain

PRMightGetPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

Missing school when he/she has pain

PRMissSchoolPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

Wanting to be alone when he/she has pain

PRAlonePain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

It is hard for him/her to run when he/she has pain

PRRunPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

It is hard for him/her to have fun when having pain

PRFunPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

Having trouble moving around when he/she has pain

PRMovePain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

It is hard for him/her to stay standing when he/she has pain

PRStandPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

It is hard for him/her to take care of himself/herself when he/she has pain

PRTakeCarePain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

It is hard for him/her to do what others can do because he/she might get pain

PROtherMightGetPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

Waking up at night when he/she has pain

PRUpAtNightPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

Getting tired when he/she has pain

PRTiredPain, #   ◎ Never ◎ Almost never ◎ Sometimes ◎ Often ◎ Almost always ◎ Not answered

PARENTP...(0/11)   PARENTW....(0/7)   PARENTE...(0/3)   ► -- Select to Jump --

Title: Worry

Subtitle: Sickle Cell Disease Module: Parent Report for Teens

How much of a problem has your child had with...

Worrying that he/she will have pain

PRWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying that other people will not know what to do if he/she has pain

PRPeopleWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying when he/she is away from home

PRWorryAwayHome, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have to go to the emergency room

PRWorryEmergency, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have to stay overnight in the hospital

PRWorryHospital, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have a stroke

PRWorryStroke, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying he/she might have a chest crisis

PRWorryChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

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PARENTW...(0/7)   PARENTE...(0/3)   PARENTS...(0/12)   ► -- Select to Jump --

Title: Emotions

Subtitle: Sickle Cell Disease Module: Parent Report for Teens

How much of a problem has your child had with...

Getting scared about having needle sticks

PRScaredNeedles, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Feeling mad about having sickle cell disease

PRMadDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Feeling mad when he/she has pain

PRMadPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Title: My child's disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module: Parent Report for Teens

How much of a problem has your child had with...

Having headaches

PRHeadaches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Getting yellow eyes when he/she is sick

PRYellowEyes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to manage his/her pain

PRManagePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to control his/her pain

PRControlPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for him/her to remember to take his/her medicine

PRTakeMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Not liking how he/she feels after taking medicine

PRFeelsMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Not liking the way his/her medicine tastes

PRTastesMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Medicine making him/her sleepy

PRSleepyMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying about whether his/her medicine is working

PRWorkingMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Worrying about whether his/her treatments are working

PRWorkingTreatments, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Medicine not making him/her feel better

PRNotFeelBetterMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Other kids make him/her feel different because how he/she looks

PRFeelsDifferent, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

PARENTS...(0/12) PARENTC...(0/6) PARENTG...(0/6) ► -- Select to Jump --

Title: Communication

Subtitle: Sickle Cell Disease Module: Parent Report for Teens

How much of a problem has your child had with...

It is hard for him/her to tell others when he/she is in pain

PRTellOtherPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to tell the doctors and nurses how he/she feels

PRTellDocsPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to ask the doctors and nurses questions

PRAskQuestions, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her when other people do not understand about his/her sickle cell disease

PRNotUnderstandDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her when other people do not understand how much pain he/she feels

PRNotUnderstandPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for him/her to tell others that he/she has sickle cell disease

PRTellOthersDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

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PARENTC...(0/6) PARENTG...(0/6) PARENTS...(0/6) ► -- Select to Jump --

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Teens

Instructions: On the following pages is a list of things that might be a problem for your teen. Please tell us how much of a problem for each one has be... There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for your child...

Feeling tired

PRFeelTired, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling physically weak (not strong)

PRFeelPhysicalWeak, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling too tired to do things that he/she likes to do

PRFeelTiredForLikes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling too tired to spend time with his/her friends

PRFeelTiredFriends, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble finishing things

PRTroubleFinish, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble starting things

PRTroubleStart, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

PARENTG...(0/6)　　**PARENTS...**(0/6)　　PARENTC...(0/6)　　► 　-- Select to Jump --

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Teens

How much of a problem has this been for your child...

Sleeping a lot

PRSleepALot, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Difficulty sleeping through the night

PRDifficultSleep, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Feeling tired when he/she wakes up in the morning

PRFeelTiredMorning, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Resting a lot

PRRestALot, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Taking a lot of naps

PRTakingNaps, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Spending a lot of time in bed

PRTimeInBed, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

---

PARENTS...(0/6)　　**PARENTC...**(0/6)　　PARENTP...(0/8)　　► 　-- Select to Jump --

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Teens

How much of a problem has this been for your child...

Difficulty keeping his/her attention on things

PRAttention, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Difficulty remembering what people tell him/her

PRRememberTold, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Difficulty remembering what he/she just heard

PRRememberHeard, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Difficulty thinking quickly

PRThinkQuick, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Trouble remembering what he/she was just thinking

PRRememberThink, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

Trouble remembering more than one thing at a time

PRRememberMoreOne, #　　○ Never　○ Almost never　○ Sometimes　○ Often　○ Almost always　○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄   PARENTC...(0/6)   **PARENTP...(0/8)**   PARENTE...(0/5)   ►   -- Select to Jump -- ▾

Title: Physical Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Teens

Instructions: On the following pages is a list of things that might be a problem for your teen. Please tell us how much of a problem for each one has been for your teen. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has your child had with...

Walking more than one block

PRWalking, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Running

PRRunning, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Participating in sports activity or exercise

PRPlayOrExercise, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Lifting something heavy

PRLiftHeavy, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Taking a bath or shower by himself/herself

PRBathing, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Doing chores around the house

PRPickUpToys, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Having hurts or aches

PRHurtsOrAches, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Low energy level

PRLowEnergy, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄   PARENTP...(0/8)   **PARENTE...(0/5)**   PARENTS...(0/5)   ►   -- Select to Jump -- ▾

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Teens

How much of a problem has your child had with...

Feeling afraid or scared

PRFeelAfraid, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling sad or blue

PRFeelSad, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Feeling angry

PRFeelAngry, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Trouble sleeping

PRTroubleSleep, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

Worrying about what will happen to him/her

PRWorrying, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTE...(0/5) **PARENTS...(0/5)** PARENTS...(0/5) ► -- Select to Jump -- ▼

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Teens

How much of a problem has your child had with...

Getting along with other teens

PRPlayWithChild, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Other teens not wanting to be his/her friend

PRNoKidsWantToPlay, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Getting teased by other teens

PRGetTeased, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Not able to do things that other teens his/her age can do

PRNotAble, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Keeping up with other teens

PRKeepingUpWithOthers, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ PARENTE...(0/5) PARENTS...(0/5) **PARENTS...(0/5)** ► -- Select to Jump -- ▼

Title: School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Parent Report for Teens

How much of a problem has your child had with...

Paying attention in class

PRPayAttention, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Forgetting things

PRForgetThings, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Keeping up with schoolwork

PRKeepUpWithSchool, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Missing school because of not feeling well

PRMissSchoolNotWell, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Missing school to go to the doctor or hospital

PRMissSchoolDoctor, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

MAGiC PedsQL Young Adult Report (ages 19-21):

YoungAd...(0/3) PainAnd...(0/9) PainImp...(0/11) ► | -- Select to Jump -- ▼

Title: Visit at which survey was completed

Please indicate at which visit this survey was completed? (select ... ▼

Visit, #

Date on which this survey was completed:

VisitDay, #

Was this survey administered to the patient?

SurveyPatient, #

YesNoS
1 = Yes
0 = No

YoungAd...(0/3) **PainAnd...(0/9)** PainImp...(0/11) ► | -- Select to Jump -- ▼

Title: About my pain and hurt

Subtitle: Sickle Cell Disease Module: Young Adult Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one has been for you. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

I hurt a lot

HurtALot, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt all over my body

HurtAllOver, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my arms

HurtArms, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my legs

HurtLegs, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my stomach

HurtStomach, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my chest

HurtChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt in my back

HurtBack, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have pain everyday

PainEveryday, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have so much pain that I need medicine

PainMedicine, # ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

PainAnd...(0/9)   **PainImp...(0/11)**   Worry (0/7)   ▶   -- Select to Jump --   ▼

Title: About my pain impact

Subtitle: Sickle Cell Disease Module: Young Adult Report

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

How much of a problem has this been for you...

Is it hard for me to do things because I might get pain

MightGetPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I miss school when I have pain

MissSchoolPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I want to be alone when I have pain

AlonePain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to run when I have pain

RunPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard to have fun when I have pain

FunPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I have trouble moving when I have pain

MovePain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard to stay standing when I have pain

StandPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to take care of myself when I have pain

TakeCarePain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to do what others can do because I might get pain

OtherMightGetPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I wake up at night when I have pain

UpAtNightPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I get tired when I have pain

TiredPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

PainImp...(0/11)   **Worry** (0/7)   Emotions (0/3)   ► -- Select to Jump -- ▼

Title: About me worrying

Subtitle: Sickle Cell Disease Module: Young Adult Report

How much of a problem has this been for you...

I worry that I will have pain

WorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry that others will not know what to do if I have pain

PeopleWorryPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry when I am away from home

WorryAwayHome, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry I might have to go to the emergency room

WorryEmergency, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry I might have to stay overnight in the hospital

WorryHospital, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry I might have a stroke

WorryStroke, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry I might have a chest crisis

WorryChest, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

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Worry (0/7)   **Emotions** (0/3)   Symptom...(0/12)   ► -- Select to Jump -- ▼

Title: About my emotions

Subtitle: Sickle Cell Disease Module: Young Adult Report

How much of a problem has this been for you...

Needle sticks scare me

ScaredNeedles, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I feel mad I have sickle cell disease

MadDisease, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I feel mad when I have pain

MadPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

QLScale
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3 = Often
4 = Almost always
97 = Not answered

Emotions (0/3)   **Symptom...(0/12)**   Communi...(0/6)   ▶   -- Select to Jump --   ▼

QLScale
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97 = Not answered

Title: About my disease: symptoms and treatment

Subtitle: Sickle Cell Disease Module: Young Adult Report

How much of a problem has this been for you...

I have headaches

Headaches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I get yellow eyes when I am sick

YellowEyes, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to manage my pain

ManagePain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to control my pain

ControlPain, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

It is hard for me to remember to take my medicine

TakeMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I do not like how I feel after I take my medicine

FeelsMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I do not like the way my medicine tastes

TastesMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

My medicine makes me sleepy

SleepyMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry about whether my medicine is working

WorkingMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

I worry about whether my treatments are working

WorkingTreatments, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

My medicine does not make me feel better

NotFeelBetterMedicine, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Other kids make me feel different because of how I look

FeelsDifferent, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always   ○ Not answered

Symptom...(0/12)	**Communi...(0/6)**	General...(0/6)	▶	-- Select to Jump -- ▼

Title: About communication

Subtitle: Sickle Cell Disease Module: Young Adult Report

How much of a problem has this been for you...

It is hard for me to tell others when I am in pain

TellOtherPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to tell the doctors and nurses how I feel

TellDocsPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to ask the doctors and nurses questions

AskQuestions, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me when others do not understand about my sickle cell disease

NotUnderstandDisease, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me when others do not understand how much pain I feel

NotUnderstandPain, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard for me to tell others that I have sickle cell disease

TellOthersDisease, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Communi...(0/6)	**General...(0/6)**	SleepFa...(0/6)	▶	-- Select to Jump -- ▼

Title: General Fatigue

Subtitle: Multidimensional Fatigue Scale: Young Adult Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one h...
There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

I feel tired

FeelTired, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I feel physically weak (not strong)

FeelPhysicalWeak, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I feel too tired to do things that I like to do

FeelTiredForLikes, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I feel too tired to spend time with my friends

FeelTiredFriends, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I have trouble finishing things

TroubleFinish, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I have trouble starting things

TroubleStart, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

MAGiC PUD Annotated eCRF, Version 1.0

◄ General...(0/6) | **SleepFa...(0/6)** | Cogniti...(0/6) ► -- Select to Jump -- ▼

Title: Sleep/Rest Fatigue

Subtitle: Multidimensional Fatigue Scale: Young Adult Report

How much of a problem has this been for you...

I sleep a lot

SleepALot, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to sleep through the night

DifficultSleep, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel tired when I wake up in the morning

FeelTiredMorning, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I rest a lot

RestALot, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I take a lot of naps

TakingNaps, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I spend a lot of time in bed

TimeInBed, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ SleepFa...(0/6) | **Cogniti...(0/6)** | Physica...(0/8) ► -- Select to Jump -- ▼

Title: Cognitive Fatigue

Subtitle: Multidimensional Fatigue Scale: Young Adult Report

How much of a problem has this been for you...

It is hard for me to keep my attention on things

Attention, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to remember what people tell me

RememberTold, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to remember what I just heard

RememberHeard, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to think quickly

ThinkQuick, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble remembering what I was just thinking

RememberThink, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble remembering more than one thing at a time

RememberMoreOne, #
○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

◄ Cogniti...(0/6) | **Physica...(0/8)** | Emotion...(0/5) | ► | -- Select to Jump -- ▾

Title: Physical Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Adult Report

Instructions: On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem for each one has been for you. There are no right or wrong answers. If you do not understand a question, please ask for help.

How much of a problem has this been for you...

It is hard for me to walk more than one block

Walking, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to run

Running, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to do sports activity or exercise

PlayOrExercise, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to lift something heavy

LiftHeavy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to take a bath or shower by myself

Bathing, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

It is hard for me to do chores around the house

PickUpToys, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I hurt or feel pain

HurtsOrAches, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have low energy

LowEnergy, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

◄ Physica...(0/8) | **Emotion...(0/5)** | SocialF...(0/5) | ► | -- Select to Jump -- ▾

Title: Emotional Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Adult Report

How much of a problem has this been for you...

I feel afraid or scared

FeelAfraid, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel sad or blue

FeelSad, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I feel angry

FeelAngry, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I have trouble sleeping

TroubleSleep, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

I worry about what will happen to me

Worrying, #   ○ Never ○ Almost never ○ Sometimes ○ Often ○ Almost always ○ Not answered

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered

Emotion...(0/5)   **SocialF...(0/5)**   WorkSch...(0/5) ▶   -- Select to Jump -- ▾

Title: Social Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Adult Report

How much of a problem has this been for you...

I have trouble getting along with other young adults

PlayWithChild, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Other young adults do not want to be my friend

NoKidsWantToPlay, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

Other young adults tease me

GetTeased, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I cannot do things that others my age can do

NotAble, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

It is hard to keep up with my peers

KeepingUpWithOthers, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

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Emotion...(0/5)   SocialF...(0/5)   **WorkSch...(0/5)** ▶   -- Select to Jump -- ▾

Title: Work and School Functioning

Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Adult Report

How much of a problem has this been for you...

It is hard to pay attention at work or school

PayAttention, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I forget things

ForgetThings, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I have trouble keeping up with my work or studies

KeepUpWithSchool, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I miss work or school because of not feeling well

MissSchoolNotWell, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

I miss work or school to go to the doctor or hospital

MissSchoolDoctor, #   ○ Never   ○ Almost never   ○ Sometimes   ○ Often   ○ Almost always   ○ Not answered

QLScale
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97 = Not answered