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
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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+).
### Eligibility (1 of 3)

**MAGiC Patient Eligibility:**

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Screening Date:</strong></td>
<td><strong>ED Time:</strong> $5</td>
</tr>
<tr>
<td><strong>ED Day:</strong></td>
<td><strong>Exclusion 1:</strong></td>
</tr>
<tr>
<td><strong>Inclusion 1:</strong></td>
<td><strong>Exclusion 2:</strong></td>
</tr>
<tr>
<td><strong>Inclusion 2:</strong></td>
<td><strong>Exclusion 3:</strong></td>
</tr>
<tr>
<td><strong>Inclusion 3:</strong></td>
<td><strong>Exclusion 4:</strong></td>
</tr>
<tr>
<td><strong>Inclusion 4:</strong></td>
<td><strong>Exclusion 5:</strong></td>
</tr>
<tr>
<td><strong>Inclusion 5:</strong></td>
<td><strong>Exclusion 6:</strong></td>
</tr>
<tr>
<td><strong>Exclusion 7:</strong></td>
<td><strong>Exclusion 8:</strong></td>
</tr>
<tr>
<td><strong>Exclusion 9:</strong></td>
<td><strong>Exclusion 10:</strong></td>
</tr>
</tbody>
</table>

#### Inclusion Criteria

1. **Is the patient between 4 and 21 years of age, inclusive?**
   - **Yes**
   - **No**

2. **Does the patient have Hb SS or Hb SB Thalassemia disease?**
   - **Yes**
   - **No**

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**

4. **Has the decision been made to admit the patient to the inpatient unit for sickle cell pain crisis?**
   - **Yes**
   - **No**

#### Exclusion Criteria

1. **Has the patient received more than 12 hours of intravenous pain medication prior to enrollment?**
   - **Yes**
   - **No**

2. **Has the patient had a previous enrollment in this study?**
   - **Yes**
   - **No**

3. **Does the patient have a history of allergy/intolerance to both intravenous morphine and hydromorphone?**
   - **Yes**
   - **No**

4. **Does the patient have a known other cause for current pain - (vascular necrosis, gall bladder disease, priapism, etc.)?**
   - **Yes**
   - **No**

5. **Has the patient had greater than 10 admissions for pain crisis in the past year?**
   - **Yes**
   - **No**

6. **Does the patient have pain from current crisis of greater than 5 days duration?**
   - **Yes**
   - **No**

7. **Is the patient maintained on daily opioids or chronic transfusions for chronic sickle cell pain?**
   - **Yes**
   - **No**

8. **Has the patient had a blood transfusion within the previous two months?**
   - **Yes**
   - **No**

9. **Does the patient have known kidney or liver failure (elevation of LFTs would not warrant exclusion)?**
   - **Yes**
   - **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 \( \geq 39.5 \, ^\circ \text{C} (103.1 \, ^\circ \text{F}) \)?
   - 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, #
## Eligibility (3 of 3)

### Is the patient eligible?
- Eligible patients have all inclusion criteria as Yes, and all exclusion criteria as No.
- Eligibility, #
  - YesNo: 1 = Yes, 0 = No

### Parental / Patient Consent: (Patient = 18 years of age)
- Was the patient/parent pre-consented?
  - 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?)
  - ConsentApproach, #
  - YesNoS: 1 = Yes, 0 = No

#### Reason why parent(s)/patient not approached for consent?
- 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?
- Consent, #
  - YesNoS: 1 = Yes, 0 = No

#### Consent time:
- ConsentDay, #
- ConsentTime, $\text{MM:SS}$

#### If parent or patient refused participation in study and offered a reason why, please provide here:
- Value not provided

### Child Assent:
- Was the child approached for assent?
  - AssentApproach, #
  - YesNoS: 1 = Yes, 0 = No

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

#### Did the child give assent?
- Assent, #
  - YesNoS: 1 = Yes, 0 = No

#### Assent time:
- AssentDay, #
- AssentTime, $\text{MM:SS}$

---

**LaterIneligible, #**
- YesNo: 1 = Yes, 0 = No

---

**Value not provided**
### MAGiC Patient Demographics:

<table>
<thead>
<tr>
<th>Demographics (1 of 1)</th>
</tr>
</thead>
</table>

#### MAGiC Patient Demographics:

**Date of birth:**

- Age, #

**Sex:**

- 1 = Male
- 2 = Female

**Ethnicity:**

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

**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

- **Ethnicity, #**

- **NIHRace, #**
MAGiC Patient Randomization:

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PtRandomized, #</td>
<td>YesNo 1 = Yes 0 = No</td>
</tr>
<tr>
<td>NotRandReason, #</td>
<td>NoRand 1 = Patient had received IV opioid medication for greater than 12 hours before randomization could be accomplished&lt;br&gt;2 = Patient developed other exclusion criteria before randomization could be accomplished&lt;br&gt;3 = Withdrawal of consent prior to randomization&lt;br&gt;90 = Other reason (specify)</td>
</tr>
<tr>
<td>NotRandReasonOther, $108</td>
<td></td>
</tr>
<tr>
<td>StratifyAge, #</td>
<td>Strat 1 = 4 to 11 years of age&lt;br&gt;2 = 12 to 21 years of age</td>
</tr>
<tr>
<td>HydroxyureaUse, #</td>
<td></td>
</tr>
<tr>
<td>RandDay, #</td>
<td></td>
</tr>
<tr>
<td>RandTime, $5</td>
<td></td>
</tr>
<tr>
<td>Value not provided</td>
<td></td>
</tr>
</tbody>
</table>

**Reason why patient was not randomized:**
- 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)
<table>
<thead>
<tr>
<th>Variable</th>
<th>Format</th>
<th>Type</th>
<th>Label</th>
<th>Algorithm / Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>AssignedTreatmentGroup</td>
<td>TrtFmt</td>
<td>#</td>
<td>Which treatment was the patient assigned to?</td>
<td></td>
</tr>
<tr>
<td>ReceivedTreatmentGroup</td>
<td>TrtFmt</td>
<td>#</td>
<td>Which treatment did the patient receive?</td>
<td></td>
</tr>
<tr>
<td>RandomizationAge</td>
<td></td>
<td>#</td>
<td>Age (in years) at Randomization</td>
<td></td>
</tr>
<tr>
<td>ITT</td>
<td>YesNo</td>
<td>#</td>
<td>Is the patient in the ITT Population?</td>
<td></td>
</tr>
<tr>
<td>PerProtocol</td>
<td>YesNo</td>
<td>#</td>
<td>Is the patient in the Per Protocol population?</td>
<td></td>
</tr>
<tr>
<td>SafetyPopulation</td>
<td>YesNo</td>
<td>#</td>
<td>Is the patient in the safety population?</td>
<td></td>
</tr>
<tr>
<td>Strata</td>
<td></td>
<td>$2</td>
<td>Treatment Strata</td>
<td></td>
</tr>
</tbody>
</table>

**Algorithm / Notes**
- **TrtFmt**
  - 1 = Placebo
  - 0 = Magnesium
- **YesNo**
  - 1 = Yes
  - 0 = No
**MAGiC Previous Medical History & History of Illness:**

<table>
<thead>
<tr>
<th>Title: Illness History</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the patient have a history of:</td>
</tr>
<tr>
<td>Acute Chest Syndrome:</td>
</tr>
<tr>
<td>Asthma:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Was the patient hospitalized for a pain crisis in the past 3 years?</th>
</tr>
</thead>
<tbody>
<tr>
<td>YesNo</td>
</tr>
<tr>
<td>1 = Yes 0 = No 92 = Unknown</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pain Crisis Visits, #</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, how many times in the past 3 years:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Title: Clinic Visit Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instructions: Please record patient’s blood pressure from most recent clinic visit (within last 12 months) when patient was well. If the clinic visit information is not available, please provide the 50th percentile information.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Most Recent WELL Clinic Visit Information:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there a blood pressure available from a well clinic visit within the past 12 months?</td>
</tr>
<tr>
<td>1 = Yes 0 = No 92 = Unknown</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If no, please record 50th percentile information.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Visit when BP was taken: (DD-MMM-YYYY)</td>
</tr>
<tr>
<td>Clinic Day, #</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinic SBP, #</th>
</tr>
</thead>
<tbody>
<tr>
<td>(mmHg)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Median SBP, #</th>
</tr>
</thead>
<tbody>
<tr>
<td>(mmHg)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Median Height, #</th>
</tr>
</thead>
<tbody>
<tr>
<td>(cm)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>History Pain Crisis, #</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, how many times in the past 3 years:</td>
</tr>
</tbody>
</table>

**MAGiC PUD Annotated eCRF, Version 1.0**
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### MedHistory (2 of 3)

<table>
<thead>
<tr>
<th>System</th>
<th>Status</th>
<th>Value provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>MHHEENT, #</td>
<td></td>
<td>Normal</td>
</tr>
<tr>
<td>MHCardio, #</td>
<td></td>
<td>Abnormal</td>
</tr>
<tr>
<td>MHRespPulm, #</td>
<td></td>
<td>Abnormal</td>
</tr>
<tr>
<td>MHGI, #</td>
<td></td>
<td>Normal</td>
</tr>
<tr>
<td>MHHepatic, #</td>
<td></td>
<td>Abnormal</td>
</tr>
<tr>
<td>MHGenitourine, #</td>
<td></td>
<td>Abnormal</td>
</tr>
</tbody>
</table>

**NormAbUk**

1 = Normal  
2 = Abnormal  
92 = Unknown

**Value not provided**
MedHistory (3 of 3)

- **Renal Review:**
  - MHRenal, #
  - Value not provided

- **Neurologic Review:**
  - MHNeuro, #
  - Value not provided

- **Psychiatric / Behavioral Review:**
  - MHPsych, #
  - Value not provided

- **Endocrine Review:**
  - MHEndo, #
  - Value not provided

- **Hematologic Review:**
  - MHHeme, #
  - Value not provided

- **Musculoskeletal Review:**
  - MHMusculo, #
  - Value not provided

- **Dermatologic Review:**
  - MHDerm, #
  - Value not provided
MAGiC Baseline Information:

### Baseline (1 of 3)

**AdmitDay, #**
**AdmitTime, $5**

**VSDay, #**
**VSTime, $5**

**Temperature, #**

**SBP, #**
**DBP, #**

**RespRate, #**

**HeartRate, #**

**Reticulocytes, #**

**Baseline_BaseHemLabs**

**Baseline_BaseElecLabs**

**Baseline_BaseChemLabs**
Baseline (2 of 3)

### Non-Opioid Medications Taken Prior to ED Arrival

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>CodedOPNonOpioidName</td>
<td>Non-Opioid Name</td>
<td>$255</td>
</tr>
<tr>
<td>NonCodedOPNonOpioidName</td>
<td>Non-Opioid Name</td>
<td>$29</td>
</tr>
<tr>
<td>OPNonOpioidTime</td>
<td>Non-Opioid Time</td>
<td>$5</td>
</tr>
<tr>
<td>OPNonOpioidTaken</td>
<td>Non-Opioid Taken</td>
<td>YesNo 1 = Yes 0 = No</td>
</tr>
<tr>
<td>OPOpioidName</td>
<td>Opioid Name</td>
<td>#</td>
</tr>
<tr>
<td>OPOpioidTaken</td>
<td>Opioid Taken</td>
<td>YesNo 1 = Yes 0 = No</td>
</tr>
<tr>
<td>OPOpioidDoseUnit</td>
<td>Dose Unit</td>
<td>1 = mg 2 = mcg 90 = other</td>
</tr>
<tr>
<td>OPOpioidDoseUnitOther</td>
<td>Dose Unit Other</td>
<td>#</td>
</tr>
<tr>
<td>OPNonOpioidTaken</td>
<td>Non-Opioid Taken</td>
<td>YesNo 1 = Yes 0 = No</td>
</tr>
<tr>
<td>EDNonOpioidName</td>
<td>Opioid Name</td>
<td>#</td>
</tr>
<tr>
<td>EDNonOpioidTaken</td>
<td>Opioid Taken</td>
<td>YesNo 1 = Yes 0 = No</td>
</tr>
<tr>
<td>EDMedNam</td>
<td>Opioid Name</td>
<td>1 = Morphine 2 = Morphine SR 3 = Hydromorphone 4 = Fentanyl 5 = Codeine 6 = Oxycodone 90 = Other (specify)</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>CodedEDNonOpioidName</td>
<td>Non-Opioid Name</td>
<td>$255</td>
</tr>
<tr>
<td>NonCodedEDNonOpioidName</td>
<td>Non-Opioid Name</td>
<td>$65</td>
</tr>
<tr>
<td>EDNonOpioidName</td>
<td>Opioid Name</td>
<td>#</td>
</tr>
<tr>
<td>EDNonOpioidDay</td>
<td>Opioid Day</td>
<td>#</td>
</tr>
<tr>
<td>EDNonOpioidTime</td>
<td>Opioid Time</td>
<td>$5</td>
</tr>
<tr>
<td>EDNonOpioidTaken</td>
<td>Opioid Taken</td>
<td>YesNo 1 = Yes 0 = No</td>
</tr>
</tbody>
</table>

---

**Notes:**
- YesNo: 1 = Yes 0 = No
- EDMedNam: 1 = Morphine 2 = Morphine SR 3 = Hydromorphone 4 = Fentanyl 5 = Codeine 6 = Oxycodone 90 = Other (specify)
### Baseline (3 of 3)

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?

<table>
<thead>
<tr>
<th>Name of Opioid</th>
<th>Other name of opioid (specify):</th>
<th>Date started: (DD-MMM-YYYY)</th>
<th>Time started: (HH:MM)</th>
<th>Date stopped: (DD-MMM-YYYY)</th>
<th>Time stopped: (HH:MM)</th>
</tr>
</thead>
<tbody>
<tr>
<td>EDOpioidName</td>
<td></td>
<td>EDOpioidNameOther</td>
<td>EDOpioidStartDay</td>
<td>EDOpioidStartTime</td>
<td>EDOpioidStopDay</td>
</tr>
<tr>
<td>EDOpioidDoseBasal</td>
<td></td>
<td>EDOpioidDoseDemand</td>
<td>EDOpioidDoseUnit</td>
<td>EDOpioidRoute</td>
<td></td>
</tr>
<tr>
<td>EDOpioidStopTime</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>EDRoute</td>
</tr>
</tbody>
</table>

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

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

- **YesNo**
  - 1 = Yes
  - 0 = No

- **DoseUnit**
  - 1 = mg
  - 2 = mcg
  - 90 = other
### Physical Exam

**OnsetPainDate, #**  
**DiseaseType, #**  
**PETime, S5**  
**PEDay, #**  
**PEWeight, #**  
**PEHEENT, #**  
**PECardio, #**  
**PERespPulm, #**  
**PEGI, #**  
**PEHepatic, #**  
**PEGU, #**

#### Present Illness Information
When did the pain start for this current sickle cell crisis?

- **OnsetPainDate, #**
- **DiseaseType, #**

**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

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

**NormAbAs**  
1 = Normal  
2 = Abnormal  
99 = Not assessed

**Value not provided**
## Physical Exam (2 of 2)

### Renal Examination Findings

- **PERenal, #**
  - Normal
  - Abnormal
  - Not assessed
  - Value not provided

### Neurologic Examination Findings

- **PENeuro, #**
  - Normal
  - Abnormal
  - Not assessed
  - Value not provided

### Psychiatric/Behavioral Examination Findings

- **PEPsych, #**
  - Normal
  - Abnormal
  - Not assessed
  - Value not provided

### Endocrine Examination Findings

- **PEEndo, #**
  - Normal
  - Abnormal
  - Not assessed
  - Value not provided

### Hematologic Examination Findings

- **PEHeme, #**
  - Normal
  - Abnormal
  - Not assessed
  - Value not provided

### Musculoskeletal Examination Findings

- **PEMusculo, #**
  - Normal
  - Abnormal
  - Not assessed
  - Value not provided

### Dermatologic Examination Findings

- **PEDerm, #**
  - Normal
  - Abnormal
  - Not assessed
  - 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
  - Value not provided

**NormAbAs**

- 1 = Normal
- 2 = Abnormal
- 99 = Not assessed

Value not provided
MAGiC Daily Data Collection:

- DailyDay, #
- DailyWeakness, #
- DailyDizziness, #
- DailyCough, #
- DailyOtherNewSymp, #
- DailyConMed, #
- DailyOpoid, #
- DailyKetorolac, #
- DailyTrans, #
- DailyACS, #
- DailyPriapism, #
- DailyStroke, #
- DailyOtherMajorEvents, #

Value not provided

YesNo
1 = Yes
0 = No

Value not provided
### Daily Study Labs

**Title:** Daily Study Labs

**Instructions:** Please note: Electrolyte and Chemistry Labs, plus Magnesium, MUST be drawn one hour after the initial. *File FOXCIR study drug infusion.*

**Were hematology labs drawn on this study day?**

<table>
<thead>
<tr>
<th>Date (DD-MM-YYYY)</th>
<th>HemLabDay, #</th>
<th>HemLabTime, $S$</th>
<th>Hematocrit, #</th>
<th>MCHC, #</th>
<th>Hgb, g/dL</th>
<th>Platelets, $\times 10^3$/uL</th>
<th>Reticulocytes, #</th>
</tr>
</thead>
</table>

**Were electrolyte labs drawn on this study day?**

<table>
<thead>
<tr>
<th>Date (DD-MM-YYYY)</th>
<th>ElecLabDay, #</th>
<th>ElecLabTime, $S$</th>
<th>Sodium, #</th>
<th>Potassium, #</th>
<th>Chloride, #</th>
<th>Bicarb, #</th>
<th>BUN, #</th>
<th>Creatinine, #</th>
</tr>
</thead>
</table>

**Were chemistry labs drawn on this study day?**

<table>
<thead>
<tr>
<th>Date (DD-MM-YYYY)</th>
<th>ChemLabDay, #</th>
<th>ChemLabTime, $S$</th>
<th>Calcium, #</th>
<th>Lactate dehydrogenase, $\text{U/L}$</th>
<th>LDH, #</th>
</tr>
</thead>
</table>

**DailyData_HemLabs**

**DailyData_ElecLabs**

**DailyData_ChemLabs**

**YesNo**

1 = Yes
0 = No
MAGiC Study Drug Administration – 1st Infusion:

### Drug Administration Information

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DrugAdmin1</strong></td>
<td></td>
<td>First infusion related details</td>
</tr>
<tr>
<td><strong>InfusionStartDay</strong></td>
<td></td>
<td>Start date for the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopDay</strong></td>
<td></td>
<td>Stop date for the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartHour</strong></td>
<td></td>
<td>Start hour for the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopHour</strong></td>
<td></td>
<td>Stop hour for the infusion</td>
</tr>
<tr>
<td><strong>InfusionDose</strong></td>
<td></td>
<td>Dose of the drug being infused</td>
</tr>
<tr>
<td><strong>InfusionStartTemp</strong></td>
<td></td>
<td>Temperature at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopTemp</strong></td>
<td></td>
<td>Temperature at the stop of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartOx</strong></td>
<td></td>
<td>Oxygen saturation at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopOx</strong></td>
<td></td>
<td>Oxygen saturation at the stop of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartBP</strong></td>
<td></td>
<td>Blood pressure at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopBP</strong></td>
<td></td>
<td>Blood pressure at the stop of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartHR</strong></td>
<td></td>
<td>Heart rate at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopHR</strong></td>
<td></td>
<td>Heart rate at the stop of the infusion</td>
</tr>
<tr>
<td><strong>MedAdminHappen</strong></td>
<td></td>
<td>Did medication administration happen?</td>
</tr>
<tr>
<td><strong>WhyNoMedAdmin</strong></td>
<td></td>
<td>Reason for not administering medication</td>
</tr>
<tr>
<td><strong>InfusionStopTime</strong></td>
<td></td>
<td>Time at which the infusion was stopped</td>
</tr>
<tr>
<td><strong>VSTime</strong></td>
<td></td>
<td>Time at which vital signs were taken</td>
</tr>
<tr>
<td><strong>InfusionStopDay</strong></td>
<td></td>
<td>Day on which the infusion was stopped</td>
</tr>
<tr>
<td><strong>InfusionStartDay</strong></td>
<td></td>
<td>Day on which the infusion started</td>
</tr>
<tr>
<td><strong>InfusionDose</strong></td>
<td></td>
<td>Dose of the drug being infused</td>
</tr>
<tr>
<td><strong>InfusionHypotension</strong></td>
<td></td>
<td>Hypotension during the infusion</td>
</tr>
<tr>
<td><strong>InfusionWarmth</strong></td>
<td></td>
<td>Warmth during the infusion</td>
</tr>
<tr>
<td><strong>InfusionOther</strong></td>
<td></td>
<td>Other observations during the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartTime</strong></td>
<td></td>
<td>Start time of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartDay</strong></td>
<td></td>
<td>Day on which the infusion started</td>
</tr>
<tr>
<td><strong>InfusionStopDay</strong></td>
<td></td>
<td>Day on which the infusion was stopped</td>
</tr>
<tr>
<td><strong>InfusionStopTime</strong></td>
<td></td>
<td>Time at which the infusion was stopped</td>
</tr>
<tr>
<td><strong>VSTime</strong></td>
<td></td>
<td>Time at which vital signs were taken</td>
</tr>
<tr>
<td><strong>InfusionStartTemp</strong></td>
<td></td>
<td>Temperature at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopTemp</strong></td>
<td></td>
<td>Temperature at the stop of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartOx</strong></td>
<td></td>
<td>Oxygen saturation at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopOx</strong></td>
<td></td>
<td>Oxygen saturation at the stop of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartBP</strong></td>
<td></td>
<td>Blood pressure at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopBP</strong></td>
<td></td>
<td>Blood pressure at the stop of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStartHR</strong></td>
<td></td>
<td>Heart rate at the start of the infusion</td>
</tr>
<tr>
<td><strong>InfusionStopHR</strong></td>
<td></td>
<td>Heart rate at the stop of the infusion</td>
</tr>
<tr>
<td><strong>DrugAdmin1_VS1</strong></td>
<td></td>
<td>VS1 vs. other related details</td>
</tr>
<tr>
<td><strong>YesNo</strong></td>
<td></td>
<td>Yes/No format for binary questions</td>
</tr>
</tbody>
</table>

### Vital Signs and Other Observations

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>VSDay</strong></td>
<td></td>
<td>Day of vital signs taken</td>
</tr>
<tr>
<td><strong>VSTime</strong></td>
<td></td>
<td>Time of vital signs taken</td>
</tr>
<tr>
<td><strong>HeartRate</strong></td>
<td></td>
<td>Heart rate recorded</td>
</tr>
<tr>
<td><strong>SBP</strong></td>
<td></td>
<td>Systolic blood pressure recorded</td>
</tr>
<tr>
<td><strong>DBP</strong></td>
<td></td>
<td>Diastolic blood pressure recorded</td>
</tr>
<tr>
<td><strong>PulseOx</strong></td>
<td></td>
<td>Oxygen saturation recorded</td>
</tr>
</tbody>
</table>

### Additional Observations

- **InfusionHypotension**
  - Value not provided
- **InfusionWarmth**
  - Value not provided
- **InfusionOther**
  - Value not provided

**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:

- **MedAdminHappen, #**
  - YesNo 1 = Yes 0 = No

- **WhyNoMedAdmin, #**

- **InfusionStartDay, #**
  - Value not provided

- **InfusionStartTime, $5**
  - Value not provided

- **InfusionStopDay, #**

- **InfusionStopTime, $5**

- **InfusionDose, #**

- **InfusionSlowed, #**

- **VSTime, $5**
  - Value not provided

- **HeartRate, #**

- **SBP, #**

- **DBP, #**

- **PulseOx, #**

- **InfusionHypotension, #**
  - Value not provided

- **InfusionWarmth, #**

- **InfusionOther, #**

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

**Note:**
- For "InfusionStopTime, $5" and "InfusionStopDay, #" fields, please record the timestamp accurately.
- For "InfusionStartDay, #" field, ensure the date is correctly entered.
- For "InfusionDose, #" field, specify the correct dose administered.
- For "InfusionSlowed, #" field, indicate if the infusion was slowed.
- For "In... endpoint (hospital discharge or 12 hours after last IV opioid administration)" field, clearly document the condition.
### MAGiC Study Drug Administration – 3rd Infusion:

#### Study Drug Administration:
- Did the study drug administration occur?
  - Yes
  - No

#### Study Drug Information:
- Start Date
- Stop Date
- Total Dose

#### Drug Admin 3
- Infusion Slowed
  - Yes
  - No
- Infusion Stop Time
  - Infusion Stop Day
- VSTime
  - VSDay
- Heart Rate
- SBP
- DBP
- Pulse Ox

#### Drug Side Effects During 3rd Infusion:
- Infusion Hypotension
  - Yes
  - No
- Infusion Warmth
  - Yes
  - No
- Infusion Other
  - Value not provided

#### Why No Medi Admin?
- Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration)
  - 1 = Yes
  - 90 = Other
- Other
  - Value not provided

#### Medi Admin Happen?
- Yes
  - 1 = Yes
  - 0 = No
- Other
  - Value not provided

#### Drug Admin 3 VS3
- Yes
  - 1 = Yes
  - 0 = No
- Other
  - Value not provided

---

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:

- **MedAdminHappen, #**
- **WhyNoMedAdmin, #**
- **Value not provided**
- **InfusionStartTime, $5**
- **InfusionStopTime, $5**
- **DrugAdmin4_VS4**
- **InfusionDose, #**
- **InfusionSlowed, #**
- **InfusionStartDay, #**
- **InfusionStopDay, #**
- **InfusionOther, #**
- **InfusionHypotension, #**
- **InfusionWarmth, #**
- **Value not provided**
- **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:

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>InfusionAdmin5_VS5</td>
<td>YesNo</td>
<td>1 = Yes, 0 = No</td>
</tr>
<tr>
<td>DrugAdmin5 (1 of 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MedAdminHappen</td>
<td>YesNo</td>
<td>1 = Yes, 0 = No</td>
</tr>
<tr>
<td>WhyNoMedAdmin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InfusionStartDay</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InfusionStopDay</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InfusionStartTime</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InfusionStopTime</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InfusionSlowled</td>
<td>YesNo</td>
<td>1 = Yes, 0 = No</td>
</tr>
<tr>
<td>InfusionDose</td>
<td>Value not provided</td>
<td></td>
</tr>
<tr>
<td>InfusionHypotension</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InfusionWarmth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InfusionOther</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WhyNo</td>
<td></td>
<td>1 = Patient has reached study endpoint (hospital discharge or 12 hours after last IV opioid administration) 90 = Other (specify)</td>
</tr>
<tr>
<td>Value not provided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
MAGiC Study Drug Administration – 6th Infusion:

DrugAdmin6 (1 of 1)

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>WhyNoMedAdmin, #</td>
<td>Value not provided</td>
</tr>
<tr>
<td>InfusionStartDay, #</td>
<td>Value not provided</td>
</tr>
<tr>
<td>InfusionStopDay, #</td>
<td>Value not provided</td>
</tr>
<tr>
<td>InfusionDose, #</td>
<td>Value not provided</td>
</tr>
<tr>
<td>InfusionSlowed, #</td>
<td>Value not provided</td>
</tr>
<tr>
<td>InfusionStart, $S5</td>
<td></td>
</tr>
<tr>
<td>InfusionStopTime, $S5</td>
<td></td>
</tr>
<tr>
<td>InfusionHypotension, #</td>
<td>Value not provided</td>
</tr>
<tr>
<td>InfusionWarmth, #</td>
<td>Value not provided</td>
</tr>
<tr>
<td>InfusionOther, #</td>
<td></td>
</tr>
<tr>
<td>Study Drug Infusion Info</td>
<td></td>
</tr>
<tr>
<td>Start Date</td>
<td></td>
</tr>
<tr>
<td>Stop Date</td>
<td></td>
</tr>
<tr>
<td>Total Dose</td>
<td></td>
</tr>
<tr>
<td>Study Drug Side Effects</td>
<td></td>
</tr>
<tr>
<td>Hypotension</td>
<td>Value not provided</td>
</tr>
<tr>
<td>Patient report of</td>
<td></td>
</tr>
<tr>
<td>Other symptoms</td>
<td></td>
</tr>
<tr>
<td>NoWhy</td>
<td></td>
</tr>
</tbody>
</table>

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

AdverseEvent (1 of 1)

AdverseEvents Log:

- **Name of Event**: AEName, $100
- **Start Date**: AEStartDay, #
- **Stop Date**: AStopDay, #
- **Outcome**: AEOutcome, #
- **Intensity**: AEIntensity, #
- **Intense**: 1 = Mild, 2 = Moderate, 3 = Severe
- **Outcome**: 1 = Death, 2 = Recovered (patient returned to baseline), 3 = Recovered with sequelae, 4 = Symptom persists
- **Action Taken**: AEActionTaken, #
- **Drug Relationship**: DrugRelationship, #
- **Expected**: AEExpected, #
- **Severity**: AESeverity, #
- **Expect**: 1 = Expected, 2 = Not Expected
- **Relation**: 1 = Not related, 2 = Possibly related, 3 = Probably related
- **YesNo**: 1 = Yes, 0 = No

**Actions**
- 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)
### Opioids given ORALLY

**Title:** Opioids given ORALLY

**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.

<table>
<thead>
<tr>
<th>Name of Opioid</th>
<th>Other name of opioid (specify):</th>
<th>Date: (DD-MM-YYYY)</th>
<th>Time given: (HHMM)</th>
<th>Total dose given:</th>
<th>Dose unit</th>
<th>Other dose unit (specify):</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>POOpioidName</strong></td>
<td>#</td>
<td><strong>POOpioidDay</strong>, #</td>
<td><strong>POOpioidTime</strong>, $S$</td>
<td><strong>POOpioidDose</strong>, #</td>
<td><strong>POOpioidDoseUnit</strong>, $S201</td>
<td><strong>POOpioidDoseUnitOther</strong>, $S255</td>
</tr>
</tbody>
</table>

**POName**

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

**DoseUnit**

- 1 = mg
- 2 = mcg
- 90 = other
**MAGiC Ketorolac Log:**

<table>
<thead>
<tr>
<th>KetDay, #</th>
<th>KetTime, $5</th>
<th>KetDose, #</th>
<th>KetDose Unit</th>
<th>KetDoseUnitOther, $201</th>
</tr>
</thead>
</table>

| Dose Unit | 1 = mg | 2 = mcg | 90 = other |

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: Acubay, Acucu, Spray, and Toradol.
MAGiC Blood Transfusion 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.

TypeBloodProduct, #
TypeBloodProductOther, $13
TransfusionVolume, #
TransStartDay, #
TransStartTime, #
TransStopDay, #
TransStopTime, #

TypeBlood
1 = Packed RBC
90 = other (specify)
**MAGiC Magnesium Log:**

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

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mg4Day, #</td>
<td>Date</td>
</tr>
<tr>
<td>Mg4Time, $5</td>
<td>Time (HH:MM)</td>
</tr>
<tr>
<td>Magnesium4, #</td>
<td>Magnesium (mg/L)</td>
</tr>
</tbody>
</table>

---

MAGiC PUD Annotated eCRF, Version 1.0
### MAGiC Serious Adverse Event Report:

#### SAE (1 of 2)

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAEIDDay</td>
<td>1</td>
</tr>
<tr>
<td>SAEReportDay</td>
<td>1</td>
</tr>
<tr>
<td>SAEName</td>
<td>Death</td>
</tr>
<tr>
<td>SAEOnsetDay</td>
<td>1</td>
</tr>
<tr>
<td>SAEOnsetTime</td>
<td>0</td>
</tr>
<tr>
<td>SAEResDay</td>
<td>1</td>
</tr>
<tr>
<td>SAEResTime</td>
<td>0</td>
</tr>
<tr>
<td>SAEAction</td>
<td>Study medication infusion slowed</td>
</tr>
<tr>
<td>SAEAbate</td>
<td>Not applicable</td>
</tr>
<tr>
<td>SAEOutcome</td>
<td>Death</td>
</tr>
<tr>
<td>SAEIntensity</td>
<td>Mild</td>
</tr>
<tr>
<td>SAERelation</td>
<td>Not related</td>
</tr>
<tr>
<td>SAEExpected</td>
<td>Not expected</td>
</tr>
<tr>
<td>SAEIDTime</td>
<td>5</td>
</tr>
<tr>
<td>SAEReportTime</td>
<td>5</td>
</tr>
<tr>
<td>SAEOnsetTime</td>
<td>5</td>
</tr>
<tr>
<td>SAEResTime</td>
<td>5</td>
</tr>
</tbody>
</table>

#### Criteria (1 of 2)

- Death
- Life threatening
- Inpatient hospitalization
- Prolonged existing hospitalization
- Persistent or significant disability or incapacity
- Congenital abnormality or birth defect
- Other (specify)

#### Action (1 of 2)

- Study medication infusion slowed
- Study medication discontinued
- Concomitant medication started, changed, or discontinued
- Surgery or other procedure
- None
- Other (describe)

#### Outcome (1 of 2)

- Death
- Recovered
- Recovered with sequelae
- Symptom persists

#### Intensity (1 of 2)

- Mild
- Moderate
- Severe

#### Relation (1 of 2)

- Not related
- Possibly related
- Probably related

#### Expected (1 of 2)

- Expected
- Not expected

#### Other (specify)

- Value not provided
MAGiC Study Summary:

- **DischargeDay, #**
- **FirstIVOpioidDay, #**
- **LastIVOpioidDay, #**
- **DischargeTime**
- **FirstIVOpioidTime**
- **LastIVOpioidTime**
- **PtDrugAssess, #**
- **DrugOn**
  - 1 = Magnesium
  - 2 = Saline
  - 92 = Patient does not know
  - 99 = Not Asked
- **FinalDiagnosis, #**
- **YesNo**
  - 1 = Yes
  - 0 = No
- **FinalDiagnosisOther, $1513**
MAGiC Telephone Follow-up:

<table>
<thead>
<tr>
<th>Field</th>
<th>Value provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>PhoneOccur, #</td>
<td></td>
</tr>
<tr>
<td>YesNo</td>
<td>1 = Yes, 0 = No</td>
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<tr>
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<tr>
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<td>1 = Yes, 0 = No</td>
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</tr>
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</tr>
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<tr>
<td>RehosLoc, #</td>
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<tr>
<td>UnCare</td>
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<td>Value not provided</td>
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</tr>
<tr>
<td>Value not provided</td>
<td></td>
</tr>
</tbody>
</table>

MAGiC PUD Annotated eCRF, Version 1.0
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, 
ChildDaysOfPainRange, 
ChildPainScale, 
OlderChildOverallPain, 
OneToTen, 
DaysB

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)

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?

OneToTen:

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

DaysB:

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

PainScale:

1 = Excellent
2 = Good
3 = Adequate
4 = Some
5 = None
MAGiC Telephone Follow-up Ages 4-18:

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>YesNo</td>
<td>1 = Yes, 0 = No</td>
</tr>
<tr>
<td>PhoneOccur</td>
<td>Phone occurrence of the patient being contacted</td>
</tr>
<tr>
<td>ParentInterview</td>
<td>Parent interview completed</td>
</tr>
<tr>
<td>ChildInterview</td>
<td>Child interview completed</td>
</tr>
<tr>
<td>Rehosp7day</td>
<td>Rehospitalization on the 7th day</td>
</tr>
<tr>
<td>RehospTime</td>
<td>Rehospitalization time</td>
</tr>
<tr>
<td>RehospLoc</td>
<td>Rehospitalization location</td>
</tr>
<tr>
<td>RehospSource</td>
<td>Source of the hospitalization information</td>
</tr>
<tr>
<td>Rehos</td>
<td>Rehospitalization location of the hospital</td>
</tr>
<tr>
<td>Source</td>
<td>Source of the information</td>
</tr>
<tr>
<td>UnCare</td>
<td>Source of the information</td>
</tr>
<tr>
<td>UnCareOther</td>
<td>Other source of the information</td>
</tr>
</tbody>
</table>

Value not provided: Indicates that no value was provided in the form.
**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.

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

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

### 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?

---

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

**ChildDaysOfPainExact, #**

**ChildDaysOfPainRange, #**

**OlderChildOverallPain_v2, #**

**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:

**PhoneOccur, #**
- Value not provided

**PatientInterview, #**
- Value not provided

**YesNoS**
- YesNoS 1 = Yes
- YesNoS 0 = No

**RehospDay, #**
- Value not provided

**PhoneAdult_PhoneRehos**
- Value not provided

**Rehos**
- 1 = Study Hospital
- 2 = Other Hospital

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

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

---

**Table: Telephonic Follow-up**

<table>
<thead>
<tr>
<th>Date: (DD-MON-YYYY)</th>
<th>Time: (HH:MM)</th>
<th>What resulted from this attempt to contact the patient?</th>
<th>Notes/Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**RehosLoc, #**
- Value not provided

**PhoneOccur, #**
- Value not provided

**PatientInterview, #**
- Value not provided

**YesNoS**
- YesNoS 1 = Yes
- YesNoS 0 = No

**RehospDischargeDay, #**
- Value not provided

**RehospTime, $5**
- Value not provided

**RehospSource, #**
- Value not provided

**Unsched7day, #**
- Value not provided

**Unscheduled Care Information:**
- Value not provided

**UnschedSource, #**
- Value not provided

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

---

**Table: Follow-Up Information**

<table>
<thead>
<tr>
<th>Date (DD-MON-YYYY)</th>
<th>Time (HH:MM)</th>
<th>What resulted from the follow-up telephone call?</th>
<th>Notes/Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**UnschedLocOther, $13**
- Value not provided

**UnCare**
- 1 = ED/Emeergent Care
- 2 = Primary Care Physician office
- 3 = Clinic
- 90 = Other (specify)
### Phone Adult (2 of 2)

**Title: Short Term Outcomes**

**Instructions:** Please answer the following questions pertaining to your experience 9 to 10 days post hospital discharge.

#### Days of school or work missed post-hospital discharge:

<table>
<thead>
<tr>
<th>School, #</th>
<th>(select one)</th>
<th>YesNoS</th>
<th>1 = Yes</th>
<th>0 = No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work, #</td>
<td>(select one)</td>
<td>YesNoS</td>
<td>1 = Yes</td>
<td>0 = No</td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th>MissedSchool, #</th>
<th>(select one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MissedWork, #</td>
<td>(select one)</td>
</tr>
</tbody>
</table>

#### Pain after hospital discharge:

- **DaysOfPainExact, #**
- **DaysOfPainRange, #**
- **DaysOfPainRange, #**

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

<table>
<thead>
<tr>
<th>OverallPain, #</th>
<th>(select one)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>PainScaleNew</th>
<th>1 = Much better</th>
<th>2 = A little better</th>
<th>3 = The same</th>
<th>4 = A little worse</th>
<th>5 = Much worse</th>
<th>6 = No pain since discharge</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>PainScale, #</th>
<th>OneToTen</th>
<th>0 = 0</th>
<th>1 = 1</th>
<th>2 = 2</th>
<th>3 = 3</th>
<th>4 = 4</th>
<th>5 = 5</th>
<th>6 = 6</th>
<th>7 = 7</th>
<th>8 = 8</th>
<th>9 = 9</th>
<th>10 = 10</th>
</tr>
</thead>
</table>

---

MAGIC PUD Annotated eCRF, Version 1.0
MAGiC Blood Transfusions Post Hospital Discharge:

**BloodTransDay, #**
**BloodTransType, #**
**BloodTransSource, #**
**BloodTransLoc, #**

**Date of most recent blood transfusion:**
- **BloodTransDay, #** (DD-MM-YYYY)
- **BloodTransType, #** (1 = Packed RBC, 90 = Other specify, 92 = Unknown)
- **BloodTransSource, #** (1 = Parent, 2 = Chart, 3 = Parent & Chart)
- **BloodTransLoc, #** (1 = Study hospital, 2 = Other hospital)

**Did the patient have a biomarker sample obtained for the follow-up visit timepoint?**
- **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?**
- **BloodTrans, #**
  - YesNoC: 1 = Yes; complete the following information
  - 0 = No; no further data collection on this form is required

**From what source was the transfusion information obtained?**
- **Source, #**
  - 1 = Parent
  - 2 = Chart
  - 3 = Parent & Chart

**Location of transfusion:**
- **Loc, #**
  - 1 = Study hospital
  - 2 = Other hospital
MAGiC Day 28 Patient Mortality:

<table>
<thead>
<tr>
<th>Date Patient Vital Status Determined:</th>
<th>Day Determined, #</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Vital Status:</td>
<td>VitalStatus, #</td>
</tr>
<tr>
<td>Patient Vital Status Data:</td>
<td>AliveStatusDay, #</td>
</tr>
</tbody>
</table>

Status
1 = Alive
2 = Dead
93 = Unable to determine
**MAGiC Withdrawal of Consent:**

**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:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Format</th>
<th>Type</th>
<th>Label</th>
<th>Algorithm / Notes</th>
</tr>
</thead>
<tbody>
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<td>Draw_Code</td>
<td>$50</td>
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<td>Draw code</td>
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<tr>
<td>sP_selectin</td>
<td>#</td>
<td></td>
<td>Plasma level of sP-selectin</td>
<td>= 0.01 if sP_selectinRaw is .o = sP_selectinRaw otherwise</td>
</tr>
<tr>
<td>sVCAM_1</td>
<td>#</td>
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</tr>
<tr>
<td>Nitrite</td>
<td>#</td>
<td></td>
<td>Plasma nitrite</td>
<td>= 0.01 if NitriteRaw is .o = NitriteRaw otherwise</td>
</tr>
<tr>
<td>IL_1b</td>
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<td></td>
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<tr>
<td>IL_6</td>
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<td></td>
<td>Plasma level of IL-6</td>
<td>= 0.01 if IL_6Raw is .o = IL_6Raw otherwise</td>
</tr>
<tr>
<td>TNFa</td>
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<tr>
<td>IFNg</td>
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<td>Plasma level of IFN-\gamma</td>
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</table>
## Pain Scores:

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<th>Algorithm / Notes</th>
</tr>
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<td>First pain score</td>
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<tr>
<td>LastPainScore</td>
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<td>Last pain score</td>
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</table>
## QL Scores:

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

**QLScores (1 of 3)**

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
<table>
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<tr>
<th>Variable</th>
<th>Format</th>
<th>Type</th>
<th>Label</th>
<th>Algorithm / Notes</th>
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<td>Child: Cognitive Fatigue Summary</td>
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<tr>
<td>c_Fatigue</td>
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<td></td>
<td>Child: PedsQL Fatigue</td>
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</tr>
<tr>
<td>c_Physical</td>
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<td>Child: Physical Functioning Summary</td>
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<tr>
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<td>c_Social</td>
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<td>Child: Social Functioning</td>
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<td>c_School</td>
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<td>Child: School Functioning</td>
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<tr>
<td>c_Psychosocial</td>
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<td>c_Generic</td>
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<td>Child: PedsQL Generic</td>
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</tr>
<tr>
<td>p_PainHurt</td>
<td>#</td>
<td></td>
<td>Parent: Pain and Hurt Summary</td>
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</tr>
<tr>
<td>p_PainImpact</td>
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<td>Parent: Pain Impact Summary</td>
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<tr>
<td>p_WorryI</td>
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<td>Parent: Worry Summary (I)</td>
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<td>p_WorryII</td>
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<td>Parent: Worry Summary (II)</td>
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<tr>
<td>p_Emotions</td>
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<td>p_PainManagement</td>
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<td>Parent: Pain Management Summary</td>
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<tr>
<td>p_Treatment</td>
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<td>Parent: Symptoms and Treatment Summary</td>
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<td>Type</td>
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<td>Parent: PedsQL Sickle Cell</td>
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<td>Parent: Physical Functioning Summary</td>
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<td>p_Emotional</td>
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<td>p_Psychosocial</td>
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<tr>
<td>Occurrence</td>
<td>#</td>
<td></td>
<td>Occurrence</td>
<td></td>
</tr>
</tbody>
</table>
MAGIC Peds Quality of Life Family Information Form Ages 4-18:

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

MomMaritalStatus, # DadMaritalStatus, #

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

MomEducation, # DadEducation, #

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

ChronicCondition, #

YesNoS
1 = Yes
0 = No

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

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

HospitalVisits, #

EDVisits, #

NumberHospitalVisits, # Hourly Limit NumHospitalVisitsPain, # Hourly Limit NumHospitalVisitsACS, #

NumberEDVisits, # Hourly Limit NumEDVisitsPain, # Hourly Limit NumEDVisitsACS, #

DaysMissSchool, # # of days DaysSick, # # of days

DaysChildcare, # # of days

ParentWork
Do you work outside the home? (If yes, please answer the following questions about your work.)

ParentNotWork, #

YesNoS
1 = Yes
0 = No

ParentMissWork, # # of days

ParentRoutine, # # of days

ParentConcentrate, # # of days

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered
MAGIC PedsQL Parent Report for Toddlers (age 4):

### Visit at which survey was completed

**Visit, #**: 
- (select one)
- Date on which this survey was completed:

**VisitDay, #**: 
- 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

**SurveyParent, #**: 
- YesNoS
  - 1 = Yes
  - 0 = No

### Pain and Hurt

**PRHurtALot, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PRHurtAllOver, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PRHurtArms, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PRHurtLegs, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PRHurtStomach, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PRHurtChest, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PRHurtBack, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PRPainEveryday, #**: 
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**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
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

<table>
<thead>
<tr>
<th>PRMightGetPain, #</th>
</tr>
</thead>
<tbody>
<tr>
<td>Missing school when he/she has pain</td>
</tr>
<tr>
<td>PRMissSchoolPain, #</td>
</tr>
<tr>
<td>Wanting to be alone when he/she has pain</td>
</tr>
<tr>
<td>PRA AlonePain, #</td>
</tr>
<tr>
<td>It is hard for him/her to run when he/she has pain</td>
</tr>
<tr>
<td>PRRunPain, #</td>
</tr>
<tr>
<td>It is hard for him/her to have fun when having pain</td>
</tr>
<tr>
<td>PRFunPain, #</td>
</tr>
<tr>
<td>Having trouble moving around when he/she has pain</td>
</tr>
<tr>
<td>PRMovePain, #</td>
</tr>
<tr>
<td>It is hard for him/her to stay standing when he/she has pain</td>
</tr>
<tr>
<td>PRStandPain, #</td>
</tr>
<tr>
<td>It is hard for him/her to take care of himself/herself when he/she has pain</td>
</tr>
<tr>
<td>PRTakeCarePain, #</td>
</tr>
<tr>
<td>It is hard for him/her to do what others can do because he/she might get pain</td>
</tr>
<tr>
<td>PROOtherMightGetPain, #</td>
</tr>
<tr>
<td>Waking up at night when he/she has pain</td>
</tr>
<tr>
<td>PRUpAtNightPain, #</td>
</tr>
<tr>
<td>Getting tired when he/she has pain</td>
</tr>
<tr>
<td>PRTiredPain, #</td>
</tr>
</tbody>
</table>

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

**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

### Emotions

**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

### Scale

QL Scale
- 0 = Never
- 1 = Almost never
- 2 = Sometimes
- 3 = Often
- 4 = Almost always
- 97 = Not answered
### My child's disease: symptoms and treatment

#### 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 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

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

**Title:** Communication

**Subtitle:** Sickle Cell Disease Module

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is hard for him/her to tell others when he/she is in pain</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>It is hard for him/her to tell the doctors and nurses how he/she feels</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>It is hard for him/her to ask the doctors and nurses questions</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>It is hard for him/her when other people do not understand about his/her sickle cell disease</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>It is hard for him/her when others do not understand how much pain he/she feels</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>It is hard for him/her to tell others that he/she has sickle cell disease</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
</tbody>
</table>

**QLScale**

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

### General Fatigue

**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 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...**

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling tired</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>Feeling physically weak (not strong)</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>Feeling too tired to do things that he/she likes to do</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>Feeling too tired to spend time with his/her friends</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>Trouble finishing things</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>Trouble starting things</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
</tbody>
</table>

**QLScale**

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

### 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

**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)**
- **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

**SurveyParent, #**
- Date on which parent survey was completed:

**SurveyChild, #**
- Date on which young child survey was completed:

**HurtALot, #**
- Do you hurt a lot

**HurtAllOver, #**
- Do you hurt all over your body

**HurtArms, #**
- Do you hurt in your arms

**HurtLegs, #**
- Do you hurt in your legs

**HurtStomach, #**
- Do you hurt in your stomach

**HurtChest, #**
- Do you hurt in your chest

**HurtBack, #**
- Do you hurt in your back

**PainEveryday, #**
- Do you have pain everyday

**PainMedicine, #**
- Do you have pain so much you need medicine

**VisitDayChild, #**
- VisitDayChild, #

**VisitDayParent, #**
- VisitDayParent, #
### Worry

**Title:** About me worrying

**Subtitle:** Sickle Cell Disease Module: Young Child Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
<th>YCScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you worry that you will have pain</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
<tr>
<td>Do you worry that other people with not know what to do if you have pain</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
<tr>
<td>Do you worry when you are away from home</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
<tr>
<td>Do you worry you might have to go to the emergency room</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
<tr>
<td>Do you worry you might have to stay overnight in the hospital</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
</tbody>
</table>

### Emotions

**Title:** About my emotions

**Subtitle:** Sickle Cell Disease Module: Young Child Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
<th>YCScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do needle sticks scare you</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
<tr>
<td>Do you feel mad you have sickle cell disease</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
<tr>
<td>Do you feel mad when you have pain</td>
<td>[ ] Not at all □ Sometimes □ A lot □ Not answered</td>
<td>0</td>
</tr>
</tbody>
</table>
Do you have headaches

Do you get yellow eyes when you are sick

Is it hard for you to manage your pain

Is it hard for you to control your pain

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

Do you not like the way your medicine tastes

Does your medicine make you sleepy

Do you worry about whether your medicine is working

Do you worry about whether your treatments are working

Does your medicine not make you feel better

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

---

**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.

- Feeling very tired
- A lot
- Not answered

**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

---

**YCScale**

0 = Not at all
2 = Sometimes
4 = A lot
97 = Not answered
### Sleep/Rest Fatigue

**Subtitle:** Multidimensional Fatigue Scale; Young Child Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you sleep a lot</td>
<td>Not at all</td>
</tr>
<tr>
<td>Is it hard for you to sleep through the night</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Do you feel tired when you wake up in the morning</td>
<td>Not at all</td>
</tr>
<tr>
<td>Do you rest a lot</td>
<td>Not at all</td>
</tr>
<tr>
<td>Do you take a lot of naps</td>
<td>Not at all</td>
</tr>
<tr>
<td>Do you spend a lot of time in bed</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

**YCScale**

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

### Cognitive Fatigue

**Subtitle:** Multidimensional Fatigue Scale; Young Child Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it hard for you to keep your attention on things</td>
<td>Not at all</td>
</tr>
<tr>
<td>Is it hard for you to remember what people tell you</td>
<td>Not at all</td>
</tr>
<tr>
<td>Is it hard for you to remember what you just heard</td>
<td>Not at all</td>
</tr>
<tr>
<td>Is it hard for you to think quickly</td>
<td>Not at all</td>
</tr>
<tr>
<td>Do you have trouble remembering what you were just thinking</td>
<td>Not at all</td>
</tr>
<tr>
<td>Do you have trouble remembering more than one thing at a time</td>
<td>Not at all</td>
</tr>
<tr>
<td>Title: Physical Functioning</td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
<td></td>
</tr>
<tr>
<td>Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Child Report</td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>YCScale: 0 = Not at all, 2 = Sometimes, 4 = A lot, 97 = Not answered</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>YCScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is hard for you to walk.</td>
<td></td>
</tr>
<tr>
<td>It is hard for you to run.</td>
<td></td>
</tr>
<tr>
<td>It is hard for you to play sports or exercise.</td>
<td></td>
</tr>
<tr>
<td>It is hard for you to play big things.</td>
<td></td>
</tr>
<tr>
<td>It is hard for you to take a bath or shower.</td>
<td></td>
</tr>
<tr>
<td>It is hard for you to do chores (like pick up your toys).</td>
<td></td>
</tr>
<tr>
<td>Do you have hurts or aches.</td>
<td></td>
</tr>
<tr>
<td>Do you ever feel too tired to play.</td>
<td></td>
</tr>
<tr>
<td>Walking, #</td>
<td></td>
</tr>
<tr>
<td>Running, #</td>
<td></td>
</tr>
<tr>
<td>PlayOrExercise, #</td>
<td></td>
</tr>
<tr>
<td>LiftHeavy, #</td>
<td></td>
</tr>
<tr>
<td>Bathing, #</td>
<td></td>
</tr>
<tr>
<td>PickUpToys, #</td>
<td></td>
</tr>
<tr>
<td>HurtsOrAches, #</td>
<td></td>
</tr>
<tr>
<td>HurtsOrAchesSpecify, $23</td>
<td></td>
</tr>
<tr>
<td>LowEnergy, #</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Title: Emotional Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtitle: Pediatric Quality of Life Inventory Acute Version: Young Child Report</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>YCScale: 0 = Not at all, 2 = Sometimes, 4 = A lot, 97 = Not answered</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>YCScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel scared.</td>
<td></td>
</tr>
<tr>
<td>Do you feel sad.</td>
<td></td>
</tr>
<tr>
<td>Do you feel mad.</td>
<td></td>
</tr>
<tr>
<td>Do you have trouble sleeping.</td>
<td></td>
</tr>
<tr>
<td>Do you worry about what will happen to you.</td>
<td></td>
</tr>
<tr>
<td>FeelAfraid, #</td>
<td></td>
</tr>
<tr>
<td>FeelSad, #</td>
<td></td>
</tr>
<tr>
<td>FeelAngry, #</td>
<td></td>
</tr>
<tr>
<td>TroubleSleep, #</td>
<td></td>
</tr>
<tr>
<td>Worrying, #</td>
<td></td>
</tr>
</tbody>
</table>

MAGIC PUD Annotated eCRF, Version 1.0
### Social Functioning

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

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

<table>
<thead>
<tr>
<th>Question</th>
<th>YCScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it hard for you to get along with other kids</td>
<td>0 = Not at all</td>
</tr>
<tr>
<td>Do other kids say they do not want to play with you</td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td>Do other kids tease you</td>
<td>4 = A lot</td>
</tr>
<tr>
<td>Can other kids do things that you cannot do</td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>Is it hard for you to keep up when you play with other kids</td>
<td></td>
</tr>
</tbody>
</table>

#### YCScale

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

### School Functioning

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

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

<table>
<thead>
<tr>
<th>Question</th>
<th>YCScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it hard for you to pay attention in school</td>
<td>0 = Not at all</td>
</tr>
<tr>
<td>Do you forget things</td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td>Is it hard to keep up with schoolwork</td>
<td>4 = A lot</td>
</tr>
<tr>
<td>Do you miss school because of not feeling good</td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>Do you miss school because you have to go to the doctor’s or hospital</td>
<td></td>
</tr>
</tbody>
</table>

#### YCScale

- 0 = Not at all
- 2 = Sometimes
- 4 = A lot
- 97 = Not answered
### 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 cause pain or be a problem for your child. Please tell us how much of a problem 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...**

<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRHurtALot, #</td>
<td>0 = Never</td>
<td>Hurting all over his/her body</td>
</tr>
<tr>
<td>PRHurtAllOver, #</td>
<td>0 = Never</td>
<td>Hurting in his/her arms</td>
</tr>
<tr>
<td>PRHurtArms, #</td>
<td>0 = Never</td>
<td>Hurting in his/her arms</td>
</tr>
<tr>
<td>PRHurtLegs, #</td>
<td>0 = Never</td>
<td>Hurting in his/her legs</td>
</tr>
<tr>
<td>PRHurtStomach, #</td>
<td>0 = Never</td>
<td>Hurting in his/her stomach</td>
</tr>
<tr>
<td>PRHurtChest, #</td>
<td>0 = Never</td>
<td>Hurting in his/her chest</td>
</tr>
<tr>
<td>PRHurtBack, #</td>
<td>0 = Never</td>
<td>Hurting in his/her back</td>
</tr>
<tr>
<td>PRPainEveryday, #</td>
<td>0 = Never</td>
<td>Having pain everyday</td>
</tr>
<tr>
<td>PRPainMedicine, #</td>
<td>0 = Never</td>
<td>Having so much pain that he/she has to take medicine</td>
</tr>
</tbody>
</table>

**QLScale**

- 0 = Never
- 1 = Almost never
- 2 = Sometimes
- 3 = Often
- 4 = Almost always
- 97 = Not answered
### Worry

**Subtitle:** Sickle Cell Disease Module: Parent Report for Young Children

- **PRWorryPain, #**
  - How much did your child worry that he/she will have pain? (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered)

- **PRPeopleWorryPain, #**
  - How much did other people worry that he/she will have pain? (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered)

- **PRWorryAwayHome, #**
  - How much did he/she worry away from home? (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered)

- **PRWorryEmergency, #**
  - How much did he/she worry when he/she was away from home? (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered)

- **PRWorryHospital, #**
  - How much did he/she worry when he/she might have to go to the emergency room? (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered)

- **PRWorryStroke, #**
  - How much did he/she worry when he/she might have a stroke? (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered)

- **PRWorryChest, #**
  - How much did he/she worry when he/she might have a chest crisis? (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered)

### Emotions

**Subtitle:** Sickle Cell Disease Module: Parent Report for Young Children

- **PSCaredNeedles, #**
  - How scared did you feel about the needle sticks? (0 = Not at all, 1 = Very much)

- **PRMadDisease, #**
  - How mad did you feel about the sickle cell disease? (0 = Not at all, 1 = Very much)

- **PRMadPain, #**
  - How mad did you feel when he/she had pain? (0 = Not at all, 1 = Very much)

### QLScale

<table>
<thead>
<tr>
<th>Value</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Never</td>
</tr>
<tr>
<td>1</td>
<td>Almost never</td>
</tr>
<tr>
<td>2</td>
<td>Sometimes</td>
</tr>
<tr>
<td>3</td>
<td>Often</td>
</tr>
<tr>
<td>4</td>
<td>Almost always</td>
</tr>
<tr>
<td>97</td>
<td>Not answered</td>
</tr>
<tr>
<td>Question</td>
<td>QL Scale Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| PRHeadaches                                                             | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRYellowEyes                                                            | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRManagePain                                                            | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRControlPain                                                           | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRFeelsMedicine                                                        | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRTastesMedicine                                                       | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRSleepyMedicine                                                        | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRWorkingMedicine                                                       | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRWorkingTreatments                                                     | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRNotFeelBetterMedicine                                                | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
|                                                                        | 97 = Not answered                                                                |
| PRFeelsDifferent                                                        | QL Scale:
|                                                                        | 0 = Never
|                                                                        | 1 = Almost never
|                                                                        | 2 = Sometimes
|                                                                        | 3 = Often
|                                                                        | 4 = Almost always
<p>|                                                                        | 97 = Not answered                                                                |</p>
<table>
<thead>
<tr>
<th>Item</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRTellOtherPain</td>
<td>QLScale</td>
</tr>
<tr>
<td>PRTellDocsPain</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRAskQuestions</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRNotUnderstandDisease</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRNotUnderstandPain</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRTellOthersDisease</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRFeelTired</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRFeelPhysicalWeak</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRFeelTiredForLikes</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRFeelTiredFriends</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRTroubleFinish</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
<tr>
<td>PRTroubleStart</td>
<td>0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered</td>
</tr>
</tbody>
</table>
### Sleep/Rest Fatigue

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

**Sleeping a lot**

- PRSleepALot, #

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

**Difficulty sleeping through the night**

- PRDifficultSleep, #

**Feeling tired when he/she wakes up in the morning**

- PRFeelTiredMorning, #

**Resting a lot**

- PRRestALot, #

**Taking a lot of naps**

- PRTakingNaps, #

**Spending a lot of time in bed**

- PRTimeInBed, #

### Cognitive Fatigue

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

**Difficulty keeping his/her attention on things**

- PRAAttention, #

**Difficulty remembering what people tell him/her**

- PRRememberTold, #

**Difficulty remembering what he/she just heard**

- PRRememberHeard, #

**Difficulty thinking quickly**

- PRTThinkQuick, #

**Trouble remembering what he/she was just thinking**

- PRRememberThink, #

**Trouble remembering more than one thing at a time**

- PRRememberMoreOne, #

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

**Title:** Physical 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 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...**

<table>
<thead>
<tr>
<th>Activity</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking</td>
<td>0 - Never</td>
</tr>
<tr>
<td>Running</td>
<td>1 - Almost never</td>
</tr>
<tr>
<td>Participating in sports activity</td>
<td>2 - Sometimes</td>
</tr>
<tr>
<td>Taking a bath or shower by himself/herself</td>
<td>3 - Often</td>
</tr>
<tr>
<td>Doing chores, like picking up his or her toys</td>
<td>4 - Almost always</td>
</tr>
<tr>
<td>Taking a bath or shower by himself/herself</td>
<td>5 - Not answered</td>
</tr>
<tr>
<td>Using stairs or ladder for aid</td>
<td>6 - Not answered</td>
</tr>
<tr>
<td>Using special equipment for help</td>
<td>7 - Not answered</td>
</tr>
<tr>
<td>Having hurts or aches</td>
<td>8 - Not answered</td>
</tr>
<tr>
<td>Low energy level</td>
<td>9 - Not answered</td>
</tr>
</tbody>
</table>

### Emotional Functioning

**Title:** Emotional Quality of Life Inventory Acute Version: Parent Report for Young Children

<table>
<thead>
<tr>
<th>Emotion</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling afraid or scared</td>
<td>0 - Never</td>
</tr>
<tr>
<td>Feeling sad or blue</td>
<td>1 - Almost never</td>
</tr>
<tr>
<td>Feeling angry</td>
<td>2 - Sometimes</td>
</tr>
<tr>
<td>Feeling angry</td>
<td>3 - Often</td>
</tr>
<tr>
<td>Worrying about what will happen to him/her</td>
<td>4 - Almost always</td>
</tr>
</tbody>
</table>

**QLScale**

- 0 = Never
- 1 = Almost never
- 2 = Sometimes
- 3 = Often
- 4 = Almost always
- 97 = Not answered
### PedsYoungChild (16 of 16)

#### 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, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Other kids not wanting to be his/her friend
  - PRNoKidsWantToPlay, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Getting teased by other children
  - PRGetTeased, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Not able to do things that other children his/her age can do
  - PRNotAble, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Keeping up when playing with other children
  - PRKeepingUpWithOthers, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

#### 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, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Forgetting things
  - PRForgetThings, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Keeping up with school activities
  - PRKeepUpWithSchool, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Missing school because of not feeling well
  - PRMissSchoolNotWell, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
  - Missing school to go to the doctor or hospital
  - PRMissSchoolDoctor, #
    - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
MAGiC PedsQL Child and Parent QOL Survey Dates:

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

VisitDayChild, #
VisitDayParent, #

SurveyChild, #
Date on which child survey was completed:

SurveyParent, #
Date on which parent survey was completed:

YesNoS
1 = Yes
0 = No
MAGiC PedsQL Parent and Child Report (ages 8-12):

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hurt a lot</td>
<td>0 = Never</td>
</tr>
<tr>
<td>Hurt all over my body</td>
<td></td>
</tr>
<tr>
<td>Hurt in my arms</td>
<td></td>
</tr>
<tr>
<td>Hurt in my legs</td>
<td></td>
</tr>
<tr>
<td>Hurt in my stomach</td>
<td></td>
</tr>
<tr>
<td>Hurt in my chest</td>
<td></td>
</tr>
<tr>
<td>I have pain everyday</td>
<td></td>
</tr>
<tr>
<td>I have pain so much that I need medicine</td>
<td></td>
</tr>
</tbody>
</table>

**YesNoS**

1 = Yes
0 = No

**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

**QLScale**

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

<table>
<thead>
<tr>
<th>Question</th>
<th>QL Scale</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>MightGetPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I miss school when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MissSchoolPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to be alone when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AlonePain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard for me to run when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RunPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard to have fun when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FunPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have trouble moving when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MovePain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard to stay standing when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>StandPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard for me to take care of myself when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TakeCarePain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard for me to do what others can do because I might get pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OtherMightGetPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wake up at night when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UpAtNightPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get tired when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TiredPain, #</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

QL Scale:
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered
### About me worrying

#### Title: About me worrying

**Subtitle: Sickle Cell Disease Module: Child Report**

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

<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>I worry that I will have pain</td>
<td>Not answered</td>
</tr>
<tr>
<td>I worry that other people will not know what to do if I have pain</td>
<td>Not answered</td>
</tr>
<tr>
<td>I worry when I am away from home</td>
<td>Not answered</td>
</tr>
<tr>
<td>I worry I might have to go to the emergency room</td>
<td>Not answered</td>
</tr>
<tr>
<td>I worry I might have to stay overnight in the hospital</td>
<td>Not answered</td>
</tr>
<tr>
<td>I worry I might have a stroke</td>
<td>Not answered</td>
</tr>
<tr>
<td>I worry I might have a chest crisis</td>
<td>Not answered</td>
</tr>
</tbody>
</table>

**WorryPain, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**PeopleWorryPain, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**WorryAwayHome, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**WorryEmergency, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**WorryHospital, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**WorryStroke, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**WorryChest, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

### About my emotions

#### Title: About my emotions

**Subtitle: Sickle Cell Disease Module: Child Report**

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

<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needle sticks scare me</td>
<td>Not answered</td>
</tr>
<tr>
<td>I feel mad I have sickle cell disease</td>
<td>Not answered</td>
</tr>
<tr>
<td>I feel mad when I have pain</td>
<td>Not answered</td>
</tr>
</tbody>
</table>

**ScaredNeedles, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**MadDisease, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**MadPain, #**

- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered
<table>
<thead>
<tr>
<th>Symptom</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have headaches</td>
<td></td>
</tr>
<tr>
<td>1. Headaches, #</td>
<td></td>
</tr>
<tr>
<td>2. I get yellow eyes when I am sick</td>
<td></td>
</tr>
<tr>
<td>3. It is hard for me to manage my pain</td>
<td></td>
</tr>
<tr>
<td>4. It is hard for me to control my pain</td>
<td></td>
</tr>
<tr>
<td>5. It is hard for me to remember to take my medicine</td>
<td></td>
</tr>
<tr>
<td>6. I do not like how I feel after I take my medicine</td>
<td></td>
</tr>
<tr>
<td>7. I do not like the way my medicine tastes</td>
<td></td>
</tr>
<tr>
<td>8. My medicine makes me sleepy</td>
<td></td>
</tr>
<tr>
<td>9. I worry about whether my medicine is working</td>
<td></td>
</tr>
<tr>
<td>10. I worry about whether my treatments are working</td>
<td></td>
</tr>
<tr>
<td>11. My medicine does not make me feel better</td>
<td></td>
</tr>
<tr>
<td>12. Other kids make me feel different because of how I look</td>
<td></td>
</tr>
</tbody>
</table>

**QLScale**

0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered
### About Communication

**Title:** About communication

**Subtitle:** Sickle Cell Disease Module: Child Report

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

<table>
<thead>
<tr>
<th>Item</th>
<th>QLScale</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>TellOtherPain</td>
<td>0 = Never</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>TellDocsPain</td>
<td>1 = Almost never</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>AskQuestions</td>
<td>2 = Sometimes</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>NotUnderstandDisease</td>
<td>3 = Often</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>NotUnderstandPain</td>
<td>4 = Almost always</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>TellOthersDisease</td>
<td>97 = Not answered</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
</tbody>
</table>

### General Fatigue

**Title:** General Fatigue

**Subtitle:** Multidimensional Fatigue Scale: Child Report

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

<table>
<thead>
<tr>
<th>Item</th>
<th>QLScale</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>FeelTired</td>
<td>0 = Never</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>FeelPhysicalWeak</td>
<td>1 = Almost never</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>FeelTiredForLikes</td>
<td>2 = Sometimes</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>FeelTiredFriends</td>
<td>3 = Often</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>TroubleFinish</td>
<td>4 = Almost always</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>TroubleStart</td>
<td>97 = Not answered</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
</tbody>
</table>
### Sleep/Rest Fatigue

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep a lot</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>It is hard for me to sleep through the night</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>I feel tired when I wake up in the morning</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>I rest a lot</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>I take a lot of naps</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>I spend a lot of time in bed</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
</tbody>
</table>

### Cognitive Fatigue

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>It is hard for me to keep my attention on things</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>It is hard for me to remember what people tell me</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>It is hard for me to remember what I just heard</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>It is hard for me to think quickly</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>I have trouble remembering what I was just thinking</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>I have trouble remembering more than one thing at a time</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
</tbody>
</table>

**QLScale**

0 = Never  
1 = Almost never  
2 = Sometimes  
3 = Often  
4 = Almost always  
97 = Not answered
### Physical Functioning

<table>
<thead>
<tr>
<th>Activity</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking</td>
<td>Never</td>
</tr>
<tr>
<td>Running</td>
<td>Almost never</td>
</tr>
<tr>
<td>Play or Exercise</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Lift Heavy</td>
<td>Often</td>
</tr>
<tr>
<td>Bathing</td>
<td>Almost always</td>
</tr>
<tr>
<td>Pick Up Toys</td>
<td>Not answered</td>
</tr>
<tr>
<td>Lift Heavy</td>
<td>Not answered</td>
</tr>
</tbody>
</table>

### Emotional Functioning

<table>
<thead>
<tr>
<th>Emotion</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel Afraid</td>
<td>Never</td>
</tr>
<tr>
<td>Feel Sad</td>
<td>Almost never</td>
</tr>
<tr>
<td>Feel Angry</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Feel Angry</td>
<td>Often</td>
</tr>
<tr>
<td>Trouble Sleep</td>
<td>Almost always</td>
</tr>
<tr>
<td>Worrying</td>
<td>Not answered</td>
</tr>
</tbody>
</table>

**QLScale**

0 = Never  
1 = Almost never  
2 = Sometimes  
3 = Often  
4 = Almost always  
97 = Not answered
### Social Functioning

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

**Title:** Social Functioning

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

### School Functioning

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

**Title:** School Functioning

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

**QL Scale**

0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRHurtALot, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRHurtAllOver, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRHurtArms, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRHurtLegs, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRHurtStomach, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRHurtChest, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRHurtBack, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRPainEveryday, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
<tr>
<td>PRPainMedicine, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
</tr>
</tbody>
</table>

**QLScale**

0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered
<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRMightGetPain, #</td>
<td>QLScale</td>
<td>0 = Never</td>
</tr>
<tr>
<td>PRMissSchoolPain, #</td>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td>PRAOnePain, #</td>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td>PRRunPain, #</td>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td>PRFunPain, #</td>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td>PRMovePain, #</td>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRStandPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRTakeCarePain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PROOtherMightGetPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRUpAtNightPain, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRTiredPain, #</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Worry

**Subtitle:** Sickle Cell Disease Module: Parent Report for Children

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worrying that he/she will have pain</td>
<td>QLScale</td>
</tr>
<tr>
<td>Worrying that other people will not know what to do if he/she has pain</td>
<td></td>
</tr>
<tr>
<td>Worrying when he/she is away from home</td>
<td></td>
</tr>
<tr>
<td>Worrying he/she might have to go to the emergency room</td>
<td></td>
</tr>
<tr>
<td>Worrying he/she might have to stay overnight in the hospital</td>
<td></td>
</tr>
<tr>
<td>Worrying he/she might have a stroke</td>
<td></td>
</tr>
<tr>
<td>Worrying he/she might have a chest crisis</td>
<td></td>
</tr>
</tbody>
</table>

### Emotions

**Subtitle:** Sickle Cell Disease Module: Parent Report for Children

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting scared about having needle sticks</td>
<td>QLScale</td>
</tr>
<tr>
<td>Feeling mad about having sickle cell disease</td>
<td></td>
</tr>
<tr>
<td>Feeling mad when he/she has pain</td>
<td></td>
</tr>
<tr>
<td>Title: My child's disease: symptoms and treatment</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Subtitle: Sickle Cell Disease Module: Parent Report for Children</td>
<td></td>
</tr>
</tbody>
</table>

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

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Having headaches</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting yellow eyes when he/she is sick</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's hard for him/her to manage his/her pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's hard for him/her to control his/her pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's hard for him/her to remember to take his/her medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not liking how he/she feels after taking medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not like the way his/her medicine tastes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicine making him/her sleepy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worrying about whether his/her medicine is working</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worrying about whether his/her treatments are working</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicine not making him/her feel better</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other kids make him/her feel different because how he/she looks</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

**Subtitle:** Sickle Cell Disease Module: Parent Report for Children

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

- **PRTellOtherPain, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRTellDocsPain, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRAskQuestions, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRNotUnderstandDisease, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRNotUnderstandPain, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRTellOthersDisease, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

### General Fatigue

**Subtitle:** Multidimensional Fatigue Scale: Parent Report for Children

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

- **PRFeelTired, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRFeelPhysicalWeak, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRFeelTiredForLikes, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRFeelTiredFriends, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRTroubleFinish, #**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

- **PRTroubleStart, #**
  - 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
### 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, #

#### Difficulty sleeping through the night
- PRDifficultSleep, #

#### Feeling tired when he/she wakes up in the morning
- PRFeeTiredMorning, #

#### Resting a lot
- PRRestALot, #

#### Taking a lot of naps
- PRTakingNaps, #

#### Spending a lot of time in bed
- PRTimelnBed, #

### 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
- PRAAttention, #

#### Difficulty remembering what people tell him/her
- PRRememberTold, #

#### Difficulty remembering what he/she just heard
- PRRememberHeard, #

#### Difficulty thinking quickly
- PRTThinkQuick, #

#### Trouble remembering what he/she was just thinking
- PRRememberThink, #

#### Trouble remembering more than one thing at a time
- PRRememberMoreOne, #

---

**QLScale**
- 0 = Never
- 1 = Almost never
- 2 = Sometimes
- 3 = Often
- 4 = Almost always
- 97 = Not answered
### Physical Functioning

**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...**

<table>
<thead>
<tr>
<th>Activity</th>
<th>0 = Never</th>
<th>1 = Almost never</th>
<th>2 = Sometimes</th>
<th>3 = Often</th>
<th>4 = Almost always</th>
<th>97 = Not answered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRWalking, #</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Running</td>
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<tr>
<td>PRRunning, #</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Participating in sports activity or exercise</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>PRPlayOrExercise, #</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Lifting something heavy</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>PRLiftHeavy, #</td>
<td></td>
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</tr>
<tr>
<td>Taking a bath or shower by themselves</td>
<td></td>
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<tr>
<td>PRBathing, #</td>
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<td></td>
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</tr>
<tr>
<td>Doing chores around the house</td>
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</tr>
<tr>
<td>PRPickUpToys, #</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Having hurts or aches</td>
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<tr>
<td>PRHurtsOrAches, #</td>
<td></td>
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<tr>
<td>Low energy level</td>
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<tr>
<td>PRLowEnergy, #</td>
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</tbody>
</table>

### Emotional Functioning

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

<table>
<thead>
<tr>
<th>Feeling</th>
<th>0 = Never</th>
<th>1 = Almost never</th>
<th>2 = Sometimes</th>
<th>3 = Often</th>
<th>4 = Almost always</th>
<th>97 = Not answered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling afraid or scared</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>PRFeelAfraid, #</td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Feeling sad or blue</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>PRFeelSad, #</td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Feeling angry</td>
<td></td>
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<td></td>
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<tr>
<td>PRFeelAngry, #</td>
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<td></td>
<td></td>
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<tr>
<td>Trouble sleeping</td>
<td></td>
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<tr>
<td>PRTroubleSleep, #</td>
<td></td>
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<td></td>
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<tr>
<td>Worrying about what will happen to him/her</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>PRWorrying, #</td>
<td></td>
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</tr>
</tbody>
</table>
MAGiC PedsQL Parent and Teen Report (ages 13-18):

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

HurtALot, #
HurtAllOver, #
HurtArms, #
HurtLegs, #
HurtStomach, #
HurtChest, #
HurtBack, #
PainEveryday, #
PainMedicine, #

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Options</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>MightGetPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td>0 = Never</td>
</tr>
<tr>
<td>MissSchoolPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td>1 = Almost never</td>
</tr>
<tr>
<td>AlonePain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td>RunPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td>3 = Often</td>
</tr>
<tr>
<td>FunPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td>4 = Almost always</td>
</tr>
<tr>
<td>MovePain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>StandPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td></td>
</tr>
<tr>
<td>TakeCarePain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td></td>
</tr>
<tr>
<td>OtherMightGetPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td></td>
</tr>
<tr>
<td>UpAtNightPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td></td>
</tr>
<tr>
<td>TiredPain, #</td>
<td>Never, Almost never, Sometimes, Often, Almost always, Not answered</td>
<td></td>
</tr>
<tr>
<td>I miss school when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to be alone when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard for me to run when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard to have fun when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have trouble moving when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard to stay standing when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard for me to take care of myself when I have pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is hard for me to do what others can do because I might get pain</td>
<td></td>
<td></td>
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<tr>
<td>Title: About me worrying</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subtitle: Sickle Cell Disease Module: Teen Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much of a problem has this been for you...</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Worry Pain**

- PeopleWorryPain, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

**Worry Away Home**

- WorryAwayHome, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

**Worry Emergency**

- WorryEmergency, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

**Worry Hospital**

- WorryHospital, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

**Worry Stroke**

- WorryStroke, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

**Worry Chest**

- WorryChest, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

---

<table>
<thead>
<tr>
<th>Title: About my emotions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtitle: Sickle Cell Disease Module: Teen Report</td>
</tr>
<tr>
<td>How much of a problem has this been for you...</td>
</tr>
</tbody>
</table>

**Scared Needles**

- ScaredNeedles, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

**Mad Disease**

- MadDisease, #
  - Never
  - Almost never
  - Sometimes
  - Often
  - Almost always
  - Not answered

**Mad 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
<table>
<thead>
<tr>
<th>QLScale Options</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 = Never</td>
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<tr>
<td>1 = Almost never</td>
<td></td>
</tr>
<tr>
<td>2 = Sometimes</td>
<td></td>
</tr>
<tr>
<td>3 = Often</td>
<td></td>
</tr>
<tr>
<td>4 = Almost always</td>
<td></td>
</tr>
<tr>
<td>97 = Not answered</td>
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</tbody>
</table>

### Symptoms and Treatment

<table>
<thead>
<tr>
<th>Symptom</th>
<th>QLScale Options</th>
<th>Description</th>
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<tbody>
<tr>
<td>Headaches</td>
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<tr>
<td>YellowEyes</td>
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<tr>
<td>ManagePain</td>
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<tr>
<td>ControlPain</td>
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<tr>
<td>TakeMedicine</td>
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<tr>
<td>FeelsMedicine</td>
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<tr>
<td>TastesMedicine</td>
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<tr>
<td>SleepyMedicine</td>
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<tr>
<td>WorkingMedicine</td>
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<tr>
<td>WorkingTreatments</td>
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<tr>
<td>NotFeelBetterMedicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FeelsDifferent</td>
<td></td>
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</tbody>
</table>
### PedsTeen (5 of 16)

#### Title: About communication

**Subtitle:** Sickle Cell Disease Module: Teen Report

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

- **TellOtherPain, #**
- **TellDocsPain, #**
- **AskQuestions, #**

**It is hard for me to tell others that I have sickle cell disease**

- **TellOthersDisease, #**

**NotUnderstandDisease, #**

**NotUnderstandPain, #**

**TellOthersDisease, #**

#### 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...**

- **FeelTired, #**
- **FeelPhysicalWeak, #**
- **FeelTiredForLikes, #**
- **FeelTiredFriends, #**
- **TroubleFinish, #**
- **TroubleStart, #**

**QLScale**

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

---

MAGiC PUD Annotated eCRF, Version 1.0
### Sleep/Rest Fatigue

**Subtitle:** Multidimensional Fatigue Scale: Teen Report

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

- **I sleep a lot**
  - SleepALot, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **It is hard for me to sleep through the night**
  - DifficultSleep, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **I feel tired when I wake up in the morning**
  - FeelTiredMorning, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **I rest a lot**
  - RestALot, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **I take a lot of naps**
  - TakingNaps, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **I spend a lot of time in bed**
  - TimeInBed, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

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

- **It is hard for me to remember what people tell me**
  - RememberTold, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **It is hard for me to remember what I just heard**
  - RememberHeard, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **It is hard for me to think quickly**
  - ThinkQuick, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **I have trouble remembering what I was just thinking**
  - RememberThink, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

- **I have trouble remembering more than one thing at a time**
  - RememberMoreOne, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
### Physical Functioning

**Title:** Physical Functioning

**Subtitle:** Pediatric Quality of Life Inventory Acute Version: Teen Report

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

1. **Walking, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

2. **Running, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

3. **PlayOrExercise, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

4. **LiftHeavy, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

5. **Bathing, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

6. **PickUpToys, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

7. **HurtsOrAches, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

8. **LowEnergy, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

### Emotional Functioning

**Title:** Emotional Functioning

**Subtitle:** Pediatric Quality of Life Inventory Acute Version: Teen Report

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

1. **FeelAfraid, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

2. **FeelSad, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

3. **FeelAngry, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

4. **TroubleSleep, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

5. **Worrying, #**
   - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
<table>
<thead>
<tr>
<th>Title: Social Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtitle: Pediatric Quality of Life Inventory Acute Version: Teen Report</td>
</tr>
<tr>
<td>How much of a problem has this been for you...</td>
</tr>
<tr>
<td>I have trouble getting along with other teens</td>
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<tr>
<td>PlayWithChild, #</td>
</tr>
<tr>
<td>NoKidsWantToPlay, #</td>
</tr>
<tr>
<td>Other teens do not want to be my friend</td>
</tr>
<tr>
<td>GetTeased, #</td>
</tr>
<tr>
<td>Other teens tease me</td>
</tr>
<tr>
<td>NotAble, #</td>
</tr>
<tr>
<td>I cannot do things that other teens my age can do</td>
</tr>
<tr>
<td>KeepingUpWithOthers, #</td>
</tr>
<tr>
<td>It is hard to keep up with my peers</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Title: School Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtitle: Pediatric Quality of Life Inventory Acute Version: Teen Report</td>
</tr>
<tr>
<td>How much of a problem has this been for you...</td>
</tr>
<tr>
<td>It is hard to pay attention in class</td>
</tr>
<tr>
<td>PayAttention, #</td>
</tr>
<tr>
<td>I forget things</td>
</tr>
<tr>
<td>ForgetThings, #</td>
</tr>
<tr>
<td>I have trouble keeping up with my schoolwork</td>
</tr>
<tr>
<td>KeepUpWithSchool, #</td>
</tr>
<tr>
<td>I miss school because of not feeling well</td>
</tr>
<tr>
<td>MissSchoolNotWell, #</td>
</tr>
<tr>
<td>I miss school to go to the doctor or hospital</td>
</tr>
<tr>
<td>MissSchoolDoctor, #</td>
</tr>
</tbody>
</table>
### Pain and Hurt

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 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...

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRHurtALot, #</td>
<td>QLScale</td>
</tr>
<tr>
<td>PRHurtAllOver, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td>PRHurtArms, #</td>
<td>1 = Almost never</td>
</tr>
<tr>
<td>PRHurtLegs, #</td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td>PRHurtStomach, #</td>
<td>3 = Often</td>
</tr>
<tr>
<td>PRHurtChest, #</td>
<td>4 = Almost always</td>
</tr>
<tr>
<td>PRHurtBack, #</td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRPainEveryday, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td>PRPainMedicine, #</td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>Question</td>
<td>Scale Options</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>PRMightGetPain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRMissSchoolPain, #</td>
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</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
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<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
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<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRAlonePain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRRunPain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRFunPain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRMovePain, #</td>
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</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRStandPain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRTakeCarePain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PROtherMightGetPain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRUpAtNightPain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>PRTiredPain, #</td>
<td>0 = Never</td>
</tr>
<tr>
<td></td>
<td>1 = Almost never</td>
</tr>
<tr>
<td></td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Almost always</td>
</tr>
<tr>
<td></td>
<td>97 = Not answered</td>
</tr>
</tbody>
</table>
### 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, #
  - QLScale: 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, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

- **Worrying when he/she is away from home**
  - PRWorryAwayHome, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

- **Worrying he/she might have to go to the emergency room**
  - PRWorryEmergency, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

- **Worrying he/she might have to stay overnight in the hospital**
  - PRWorryHospital, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

- **Worrying he/she might have a stroke**
  - PRWorryStroke, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

- **Worrying he/she might have a chest crisis**
  - PRWorryChest, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

### 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, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

- **Feeling mad about having sickle cell disease**
  - PRMadDisease, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered

- **Feeling mad when he/she has pain**
  - PRMadPain, #
  - QLScale: Never, Almost never, Sometimes, Often, Almost always, Not answered
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Score</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRHeadaches</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRYellowEyes</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRManagePain</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRControlPain</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRTakeMedicine</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRFeelsMedicine</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRTastesMedicine</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRSleepyMedicine</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRWorkingMedicine</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRWorkingTreatments</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRNotFeelBetterMedicine</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
<tr>
<td>PRFeelsDifferent</td>
<td>Never</td>
<td>0</td>
<td>Not answered</td>
</tr>
</tbody>
</table>

**QLScale**

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

Subitle: 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

### General Fatigue

Subtitle: Multidimensional Fatigue Scale: Parent Report for Teens

#### 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 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
### Sleep/Rest Fatigue

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

**Difficulty sleeping through the night**
- **PRDifficultSleep, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Feeling tired when he/she wakes up in the morning**
- **PRFeelTiredMorning, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Resting a lot**
- **PRRestALot, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Taking a lot of naps**
- **PRTakingNaps, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Spending a lot of time in bed**
- **PRTimeInBed, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

### Cognitive Fatigue

**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**
- **PRAAttention, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Difficulty remembering what people tell him/her**
- **PRRememberTold, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Difficulty remembering what he/she just heard**
- **PRRememberHeard, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Difficulty thinking quickly**
- **PRThinkQuick, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Trouble remembering what he/she was just thinking**
- **PRRememberThink, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered

**Trouble remembering more than one thing at a time**
- **PRRememberMoreOne, #**  
- **QLScale**
  - 0 = Never
  - 1 = Almost never
  - 2 = Sometimes
  - 3 = Often
  - 4 = Almost always
  - 97 = Not answered
### 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 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...**

<table>
<thead>
<tr>
<th>Activity</th>
<th>QLScale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Running</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PlayOrExercise, #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LiftHeavy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PickUpToys</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LiftHeavy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HurtsOrAches</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LowEnergy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Emotional Functioning

**Subtitle**: Pediatric Quality of Life Inventory Acute Version: Parent Report for Teens

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

<table>
<thead>
<tr>
<th>Emotion</th>
<th>QLScale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel afraid or scared</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel sad or blue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel angry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble sleeping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worrying</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**QLScale**

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

*Other teens not wanting to be his/her friend*

- PRNoKidsWantToPlay, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

**Getting teased by other teens**

- PRGetTeased, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

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

- PRNotAble, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

**Keeping up with other teens**

- PRKeepingUpWithOthers, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

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

**Forgetting things**

- PRForgetThings, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

**Keeping up with schoolwork**

- PRKeepUpWithSchool, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

**Missing school because of not feeling well**

- PRMissSchoolNotWell, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered

**Missing school to go to the doctor or hospital**

- PRMissSchoolDoctor, #
  - QLScale: 0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, 4 = Almost always, 97 = Not answered
MAGiC PedsQL Young Adult Report (ages 19-21):

Visit, #
SurveyPatient, #
YesNoS
1 = Yes
0 = No
VisitDay, #

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

HurtALot, #
HurtAllOver, #
HurtArms, #
HurtLegs, #
HurtStomach, #
HurtChest, #
HurtBack, #
PainEveryday, #
PainMedicine, #

QLScale
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered
<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Might Get Pain, #</td>
<td>Never</td>
</tr>
<tr>
<td>Miss School Pain, #</td>
<td>Almost never</td>
</tr>
<tr>
<td>I want to be alone when I have pain</td>
<td>Sometimes</td>
</tr>
<tr>
<td>It is hard for me to run when I have pain</td>
<td>Often</td>
</tr>
<tr>
<td>It is hard to have fun when I have pain</td>
<td>Almost always</td>
</tr>
<tr>
<td>Move Pain, #</td>
<td>Not answered</td>
</tr>
<tr>
<td>Stand Pain, #</td>
<td>Never</td>
</tr>
<tr>
<td>It is hard for me to take care of myself when I have pain</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Other Might Get Pain, #</td>
<td>Often</td>
</tr>
<tr>
<td>Up At Night Pain, #</td>
<td>Not answered</td>
</tr>
<tr>
<td>I get tired when I have pain</td>
<td>Almost never</td>
</tr>
</tbody>
</table>
### About me worrying

**Subtitle:** Sickle Cell Disease Module: Young Adult Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>WorryPain</td>
<td>0 = Never</td>
</tr>
</tbody>
</table>

- I worry that I will have pain
- I worry that others will not know what to do if I have pain
- I worry when I am away from home
- I worry I might have to go to the emergency room
- I worry I might have to stay overnight in the hospital
- I worry I might have a stroke
- I worry I might have a chest crisis

### About my emotions

**Subtitle:** Sickle Cell Disease Module: Young Adult Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>ScaredNeedles</td>
<td>0 = Never</td>
</tr>
</tbody>
</table>

- Needle sticks scare me
- I feel mad I have sickle cell disease
- I feel mad when I have pain
<table>
<thead>
<tr>
<th>Symptom</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headaches</td>
<td>0 = Never</td>
</tr>
<tr>
<td>Yellow Eyes</td>
<td>1 = Almost never</td>
</tr>
<tr>
<td>Manage Pain</td>
<td>2 = Sometimes</td>
</tr>
<tr>
<td>Control Pain</td>
<td>3 = Often</td>
</tr>
<tr>
<td>Take Medicine</td>
<td>4 = Almost always</td>
</tr>
<tr>
<td>Feels Medicine</td>
<td>97 = Not answered</td>
</tr>
<tr>
<td>Tastes Medicine</td>
<td></td>
</tr>
<tr>
<td>Sleepy Medicine</td>
<td></td>
</tr>
<tr>
<td>Working Medicine</td>
<td></td>
</tr>
<tr>
<td>Working Treatments</td>
<td></td>
</tr>
<tr>
<td>Not Feel Better Medicine</td>
<td></td>
</tr>
<tr>
<td>Feels Different</td>
<td></td>
</tr>
</tbody>
</table>

*QLScale:
0 = Never
1 = Almost never
2 = Sometimes
3 = Often
4 = Almost always
97 = Not answered*
### Title: About communication

**Subtitle:** Sickle Cell Disease Module: Young Adult Report

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

**Tell Other Pain, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Tell Docs Pain, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Ask Questions, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Not Understand Disease, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Not Understand Pain, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Tell Others Disease, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

### QLScale

<table>
<thead>
<tr>
<th>Value</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Never</td>
</tr>
<tr>
<td>1</td>
<td>Almost never</td>
</tr>
<tr>
<td>2</td>
<td>Sometimes</td>
</tr>
<tr>
<td>3</td>
<td>Often</td>
</tr>
<tr>
<td>4</td>
<td>Almost always</td>
</tr>
<tr>
<td>97</td>
<td>Not answered</td>
</tr>
</tbody>
</table>

#### 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.

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

**Feel Tired, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Feel Physical Weak, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Feel Tired For Likes, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Feel Tired For Friends, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Trouble Finish, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered

**Trouble Start, #**
- Never
- Almost never
- Sometimes
- Often
- Almost always
- Not answered
### Sleep/Rest Fatigue

**Title:** Multidimensional Fatigue Scale: Young Adult Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>I sleep a lot</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>It is hard for me to sleep through the night</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>I feel tired when I wake up in the morning</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>I rest a lot</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>I take a lot of naps</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>I spend a lot of time in bed</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
</tbody>
</table>

### Cognitive Fatigue

**Title:** Multidimensional Fatigue Scale: Young Adult Report

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

<table>
<thead>
<tr>
<th>Question</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>It's hard for me to keep my attention on things</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>It's hard for me to remember what people tell me</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>It's hard for me to remember what I just heard</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>It's hard for me to think quickly</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>I have trouble remembering what I was just thinking</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
<tr>
<td>I have trouble remembering more than one thing at a time</td>
<td>0 = Never 1 = Almost never 2 = Sometimes 3 = Often 4 = Almost always 97 = Not answered</td>
</tr>
</tbody>
</table>
### Physical Functioning

**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...**

<table>
<thead>
<tr>
<th>Activity</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking, #</td>
<td></td>
</tr>
<tr>
<td>Running, #</td>
<td></td>
</tr>
<tr>
<td>PlayOrExercise, #</td>
<td></td>
</tr>
<tr>
<td>LiftHeavy, #</td>
<td></td>
</tr>
<tr>
<td>Bathing, #</td>
<td></td>
</tr>
<tr>
<td>PickUpToys, #</td>
<td></td>
</tr>
<tr>
<td>HurtsOrAches, #</td>
<td></td>
</tr>
<tr>
<td>LowEnergy, #</td>
<td></td>
</tr>
</tbody>
</table>

**QLScale**

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

### Emotional Functioning

**Title:** Emotional 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...**

<table>
<thead>
<tr>
<th>Emotion</th>
<th>QLScale</th>
</tr>
</thead>
<tbody>
<tr>
<td>FeelAfraid, #</td>
<td></td>
</tr>
<tr>
<td>FeelSad, #</td>
<td></td>
</tr>
<tr>
<td>FeelAngry, #</td>
<td></td>
</tr>
<tr>
<td>TroubleSleep, #</td>
<td></td>
</tr>
<tr>
<td>Worrying, #</td>
<td></td>
</tr>
</tbody>
</table>

**QLScale**

0 = Never  
1 = Almost never  
2 = Sometimes  
3 = Often  
4 = Almost always  
97 = Not answered
### Social Functioning

**Title:** Social Functioning  
**Subtitle:** Pediatric Quality of Life Inventory Acute Version: Young Adult Report

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

1. I have trouble getting along with other young adults

#### PlayWithChild, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

2. Other young adults do not want to be my friend

#### NoKidsWantToPlay, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

3. Other young adults tease me

#### GetTeased, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

4. I cannot do things that others my age can do

#### NotAble, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

5. It is hard to keep up with my peers

#### KeepingUpWithOthers, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

### Work and School Functioning

**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...**

1. It is hard to pay attention at work or school

#### PayAttention, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

2. I forget things

#### ForgetThings, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

3. I have trouble keeping up with my work or studies

#### KeepUpWithSchool, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

4. I miss work or school because of not feeling well

#### MissSchoolNotWell, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Often</th>
<th>4</th>
<th>Almost always</th>
<th>97</th>
<th>Not answered</th>
</tr>
</thead>
</table>

5. I miss work or school to go to the doctor or hospital

#### MissSchoolDoctor, #

<table>
<thead>
<tr>
<th>QLScale</th>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Almost never</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
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</table>

QLScale  
0 = Never  
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