# C-Data 5.2 Annotated CRF

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### Study Phase 5000: Enrollment Visit

## Study Phase 6000: Annual Visit

## Study Phase 7000: Annual Interviews



## Study Phase 8000: Termination Visit

| Comprehensive Sickle Cell Centers | **Enrollment Form** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: ENRL:COMPDA / ENRL:COMPMO / ENRL:COMPYR (DD / MMM / YYYY)<br>Form Completed by: ENRL:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

Date of Birth: ENRL:BIRTHDA / ENRL:BIRTHMO / ENRL:BIRTHYR (DD / MMM / YYYY)

Gender:
- ☐ (ENRL:GENDER) Male
- ☐ (ENRL:GENDER) Female

Diagnosis: *(choose one)*
- ☐ (ENRL:DIAG) SS ☐ (ENRL:DIAG) SC ☐ (ENRL:DIAG) Sβ+ ☐ (ENRL:DIAG) Sβ0
- ☐ (ENRL:DIAG) S Other, specify ENRL:DIAGSP

Did this patient enroll at time of a:
- ☐ (ENRL:ENRLTM) Clinical Encounter (clinical encounter includes a visit such as a routine follow-up, transfusion, research study, medications, acute visit, ED visit, or hospital admission)

**OR**

- ☐ (ENRL:ENRLTM) Special Study enrollment visit for Patient Database

Date patient signed Informed Consent/Authorization: ENRL:INFRMDA / ENRL:INFRMMO / ENRL:INFRMYR (DD / MMM / YYYY)

Date of most recent clinical encounter: *(including enrollment encounter, if applicable)* ENRL:ENCDA / ENRL:ENCMO / ENRL:ENCYR (DD / MMM / YYYY)

Comments for page:

ENRL:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form Part I | Page: {section.pageNumber} |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: MDH1:COMPDA / MDH1:COMPMO / MDH1:COMPYR (DD / MMM / YYYY)<br>Form Completed by: MDH1:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

Date patient first seen in your center: MDH1:CNTDA / MDH1:CNTMO / MDH1:CNTYR (DD / MMM / YYYY)

Was the patient's sickle cell diagnosis detected by newborn screening?

☐ (MDH1:NEWSCR) Yes ☐ (MDH1:NEWSCR) No ☐ (MDH1:NEWSCR) Unknown

Weight: MDH1:WT ☐ (MDH1:WTUNIT) lb ☐ (MDH1:WTUNIT) kg

Height: MDH1:HT ☐ (MDH1:HTUNIT) in ☐ (MDH1:HTUNIT) cm

*See guidelines for specific instructions.*

Date of weight measurement: MDH1:WTDA / MDH1:WTMO / MDH1:WTYR (DD / MMM / YYYY)

Date of height measurement: MDH1:HTDA / MDH1:HTMO / MDH1:HTYR (DD / MMM / YYYY)

Is this patient currently participating in a research study? ☐ (MDH1:CURSTUD) Yes ☐ (MDH1:CURSTUD) No

**For CSCC studies, please check "Yes" even if study participation has been completed.**

*[If Yes]* **Check all that apply**

☐ (MDH1:ARGINE) **Arginine**

☐ (MDH1:NEURO) **Neuropsych**

☐ (MDH1:HUMAG) **Hydroxyurea-Magnesium**

☐ (MDH1:PRIAP) **Priapism** (multi-center)

☐ (MDH1:DEXAM) **Dexamethasone**

☐ (MDH1:DECIT) **Decitabine**

☐ (MDH1:METHA) **Methadone**

☐ (MDH1:WTCN) **Within-Center Study** (specify)
MDH1:WTCNSP

☐ (MDH1:OTHST) **Other Study** (specify)
MDH1:OTHSTSP

***There are no restrictions on participation in C-Data. However, there may be restrictions in other studies that would prohibit participation in C-Data. Please consult the inclusion/exclusion criteria for other studies in which this patient is currently enrolled.***

Comments for page:
MDH1:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form Part I Surgical History | Page: {section.pageNumber} |
|---|---|---|
| Collaborative Data Project | Date Form Completed: SURG:COMPDA / SURG:COMPMO / SURG:COMPYR (DD / MMM / YYYY)<br>Form Completed by: SURG:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

## Surgical History

**To the best of your knowledge, has this patient *ever* had a ...**

*(If the patient has had the same surgery more than once, please record the most recent procedure.)*

| | Yes | Year | No | Unknown |
|---|---|---|---|---|
| Tonsillectomy/Adenoidectomy<br>☐ (SURG:TONSLFR) 1 Time ☐ (SURG:TONSLFR) >1 Time | ☐ (SURG:TONSL) | SURG:TONSLYR | ☐ (SURG:TONSL) | ☐ (SURG:TONSL) |
| Splenectomy | ☐ (SURG:SPLEN) | SURG:SPLENYR | ☐ (SURG:SPLEN) | ☐ (SURG:SPLEN) |
| Cholecystectomy | ☐ (SURG:CHOL) | SURG:CHOLYR | ☐ (SURG:CHOL) | ☐ (SURG:CHOL) |
| Hip Core Procedure | ☐ (SURG:HIPCO) | SURG:HIPCOYR | ☐ (SURG:HIPCO) | ☐ (SURG:HIPCO) |
| Hip Replacement<br>☐ (SURG:HIPRFR) 1 Time ☐ (SURG:HIPRFR) >1 Time | ☐ (SURG:HIPR) | SURG:HIPRYR | ☐ (SURG:HIPR) | ☐ (SURG:HIPR) |
| Laser Procedure of the Eye(s) | ☐ (SURG:LASER) | SURG:LASERYR | ☐ (SURG:LASER) | ☐ (SURG:LASER) |
| Vitrectomy | ☐ (SURG:VITRE) | SURG:VITREYR | ☐ (SURG:VITRE) | ☐ (SURG:VITRE) |
| Insertion of a Permanent Indwelling Line<br>☐ (SURG:PLINEFR) 1 Time ☐ (SURG:PLINEFR) >1 Time | ☐ (SURG:PLINE) | SURG:PLINEYR | ☐ (SURG:PLINE) | ☐ (SURG:PLINE) |
| Removal of a Permanent Indwelling Line<br>☐ (SURG:RPLINFR) 1 Time ☐ (SURG:RPLINFR) >1 Time | ☐ (SURG:RPLINE) | SURG:RPLINYR | ☐ (SURG:RPLINE) | ☐ (SURG:RPLINE) |
| Other, specify<br>SURG:SURG1SP | | SURG:SURG1YR | | |
| Other, specify<br>SURG:SURG2SP | | SURG:SURG2YR | | |
| Other, specify<br>SURG:SURG3SP | | SURG:SURG3YR | | |

Comments for page:

SURG:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form Part I Medical Conditions | Pages: 3 of 10 |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: MDC1:COMPDA (DD) / MDC1:COMPMO (MMM) / MDC1:COMPYR (YYYY)<br>Form Completed by: MDC1:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Has this patient *ever* had or *ever* been diagnosed with...**

| Yes | Year of First Diagnosis | No | Unknown | |
|---|---|---|---|---|
| ☐ (MDC1:COND1) | MDC1:CND1YR | ☐ (MDC1:COND1) | ☐ (MDC1:COND1) | (Anemia) Aplastic Episode |
| ☐ (MDC1:COND2) | MDC1:CND2YR | ☐ (MDC1:COND2) | ☐ (MDC1:COND2) | (Anemia) Immune and Non-immune Hemolysis/Hyperhemolysis |
| ☐ (MDC1:COND3) | MDC1:CND3YR | ☐ (MDC1:COND3) | ☐ (MDC1:COND3) | (Anemia) Other Anemia |
| ☐ (MDC1:COND4) | MDC1:CND4YR | ☐ (MDC1:COND4) | ☐ (MDC1:COND4) | (Anemia) Acute Splenic Sequestration |
| ☐ (MDC1:COND5) | MDC1:CND5YR | ☐ (MDC1:COND5) | ☐ (MDC1:COND5) | (Cardiac) Cardiomyopathy |
| ☐ (MDC1:COND6) | MDC1:CND6YR | ☐ (MDC1:COND6) | ☐ (MDC1:COND6) | (Cardiac) Hypertension |
| ☐ (MDC1:COND7) | MDC1:CND7YR | ☐ (MDC1:COND7) | ☐ (MDC1:COND7) | (Cardiac) Mitral Valve Prolapse |
| ☐ (MDC1:COND8) | MDC1:CND8YR | ☐ (MDC1:COND8) | ☐ (MDC1:COND8) | (Cardiac) Myocardial Infarction |
| ☐ (MDC1:COND9) | MDC1:CND9YR | ☐ (MDC1:COND9) | ☐ (MDC1:COND9) | (CNS) Seizure |
| ☐ (MDC1:COND10) | MDC1:CND10YR | ☐ (MDC1:COND10) | ☐ (MDC1:COND10) | (CNS) Stroke-Hemorrhagic |

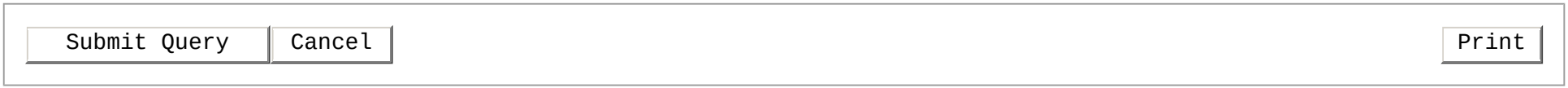
| | | | | |
|---|---|---|---|---|
| ☐ (MDC1:COND11) | MDC1:CND11YR | ☐ (MDC1:COND11) | ☐ (MDC1:COND11) | (CNS) Stroke-Infarctive |
| ☐ (MDC1:COND12) | MDC1:CND12YR | ☐ (MDC1:COND12) | ☐ (MDC1:COND12) | (CNS) Stroke-Silent Cerebral Infact |
| ☐ (MDC1:COND13) | MDC1:CND13YR | ☐ (MDC1:COND13) | ☐ (MDC1:COND13) | (CNS) Elevated Transcranial Doppler (TCD) Velocities |
| ☐ (MDC1:COND14) | MDC1:CND14YR | ☐ (MDC1:COND14) | ☐ (MDC1:COND14) | (CNS) Transient Ischemic Attack (TIA) |
| ☐ (MDC1:COND15) | MDC1:CND15YR | ☐ (MDC1:COND15) | ☐ (MDC1:COND15) | (GI/Hepatobiliary) Cholecystitis |
| ☐ (MDC1:COND16) | MDC1:CND16YR | ☐ (MDC1:COND16) | ☐ (MDC1:COND16) | (GI/Hepatobiliary) Cholelithiasis/Sludge |
| ☐ (MDC1:COND17) | MDC1:CND17YR | ☐ (MDC1:COND17) | ☐ (MDC1:COND17) | (GI/Hepatobiliary) Hepatic Sequestration |
| ☐ (MDC1:COND18) | MDC1:CND18YR | ☐ (MDC1:COND18) | ☐ (MDC1:COND18) | (GI/Hepatobiliary) Intrahepatic Cholestasis |
| ☐ (MDC1:COND19) | MDC1:CND19YR | ☐ (MDC1:COND19) | ☐ (MDC1:COND19) | (GI/Hepatobiliary) Pancreatitis |
| ☐ (MDC1:COND20) | MDC1:CND20YR | ☐ (MDC1:COND20) | ☐ (MDC1:COND20) | (GI/Hepatobiliary) Viral Hepatitis |
| ☐ (MDC1:COND21) | MDC1:CND21YR | ☐ (MDC1:COND21) | ☐ (MDC1:COND21) | (Muscular, Skeletal, Skin) Avascular Necrosis |
| ☐ (MDC1:COND22) | MDC1:CND22YR | ☐ (MDC1:COND22) | ☐ (MDC1:COND22) | (Muscular, Skeletal, Skin) Dactylitis (Hand Foot Syndrome) |
| ☐ (MDC1:COND23) | MDC1:CND23YR | ☐ (MDC1:COND23) | ☐ (MDC1:COND23) | (Muscular, Skeletal, Skin) Leg Ulcers |
| ☐ (MDC1:COND24) | MDC1:CND24YR | ☐ (MDC1:COND24) | ☐ (MDC1:COND24) | (Muscular, Skeletal, Skin) Osteomyelitis (Acute or Chronic) |
| ☐ (MDC1:COND25) | MDC1:CND25YR | ☐ (MDC1:COND25) | ☐ (MDC1:COND25) | (Ocular) Retinopathy |
| ☐ (MDC1:COND26) | MDC1:CND26YR | ☐ (MDC1:COND26) | ☐ (MDC1:COND26) | (Pain) Acute Multi-organ Failure |
| ☐ (MDC1:COND27) | MDC1:CND27YR | ☐ (MDC1:COND27) | ☐ (MDC1:COND27) | (Pain) Neuropathy (Neuropathic Pain) |
| ☐ (MDC1:COND28) | MDC1:CND28YR | ☐ (MDC1:COND28) | ☐ (MDC1:COND28) | (Pain) Sickle Cell Pain |
| ☐ (MDC1:COND29) | MDC1:CND29YR | ☐ (MDC1:COND29) | ☐ (MDC1:COND29) | (Pulmonary) Acute Chest Syndrome |

| | | | | |
|---|---|---|---|---|
| ☐ (MDC1:COND30) | MDC1:CND30YR | ☐ (MDC1:COND30) | ☐ (MDC1:COND30) | (Pulmonary) Chronic Obstructive Lung Disease |
| ☐ (MDC1:COND31) | MDC1:CND31YR | ☐ (MDC1:COND31) | ☐ (MDC1:COND31) | (Pulmonary) Chronic Restrictive Lung Disease |
| ☐ (MDC1:COND32) | MDC1:CND32YR | ☐ (MDC1:COND32) | ☐ (MDC1:COND32) | (Pulmonary) Pulmonary Embolism |
| ☐ (MDC1:COND33) | MDC1:CND33YR | ☐ (MDC1:COND33) | ☐ (MDC1:COND33) | (Pulmonary) Pulmonary Hypertension |
| ☐ (MDC1:COND34) | MDC1:CND34YR | ☐ (MDC1:COND34) | ☐ (MDC1:COND34) | (Pulmonary) Persistent Reactive Airways Disease (Asthma) |
| ☐ (MDC1:COND35) | MDC1:CND35YR | ☐ (MDC1:COND35) | ☐ (MDC1:COND35) | (Renal/Genitourinary) Acute Renal Failure |
| ☐ (MDC1:COND36) | MDC1:CND36YR | ☐ (MDC1:COND36) | ☐ (MDC1:COND36) | (Renal/Genitourinary) Chronic Renal Insufficiency |
| ☐ (MDC1:COND37) | MDC1:CND37YR | ☐ (MDC1:COND37) | ☐ (MDC1:COND37) | (Renal/Genitourinary) Hematuria |
| ☐ (MDC1:COND38) | MDC1:CND38YR | ☐ (MDC1:COND38) | ☐ (MDC1:COND38) | (Renal/Genitourinary) Priapism |
| ☐ (MDC1:COND39) | MDC1:CND39YR | ☐ (MDC1:COND39) | ☐ (MDC1:COND39) | (Renal/Genitourinary) Proteinuria/Nephrotic Syndrome |
| ☐ (MDC1:COND40) | MDC1:CND40YR | ☐ (MDC1:COND40) | ☐ (MDC1:COND40) | (Renal/Genitourinary) Pyelonephritis |
| ☐ (MDC1:COND41) | MDC1:CND41YR | ☐ (MDC1:COND41) | ☐ (MDC1:COND41) | (Splenic) Splenic Infarction |
| ☐ (MDC1:COND42) | MDC1:CND42YR | ☐ (MDC1:COND42) | ☐ (MDC1:COND42) | (Splenic) Chronic Hypersplenism |
| ☐ (MDC1:COND43) | MDC1:CND43YR | ☐ (MDC1:COND43) | ☐ (MDC1:COND43) | (Transfusions/Iron Overload) Transfusional Hemosiderosis |
| ☐ (MDC1:COND44) | MDC1:CND44YR | ☐ (MDC1:COND44) | ☐ (MDC1:COND44) | Bacteremia/Sepsis/Meningitis |

Comments for page:

MDC1:COMTXT

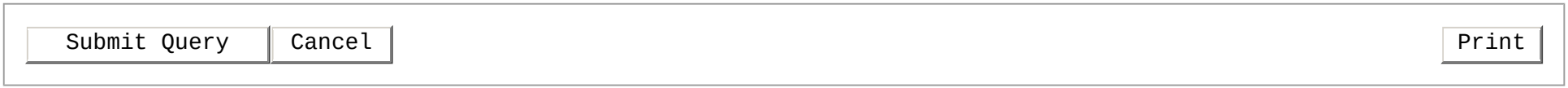
Form Completion Help


Submit Query
Cancel
Print

| Comprehensive Sickle Cell Centers | Medical History Form Part I Selected Medications | Page: {section.pageNumber} |
|---|---|---|
| Collaborative Data Project | Date Form Completed: SMED:COMPDA (DD) / SMED:COMPMO (MMM) / SMED:COMPYR (YYYY)<br>Form Completed by: SMED:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

From the list below, record all medications used by the patient in the **past year** and **prior to the past year.**

| Medications | In the Past Year | | | Prior to the Past Year | | | Specify |
|---|---|---|---|---|---|---|---|
| | Yes | No | Unk | Yes | No | Unk | |
| Hydroxyurea | ☐ (SMED:HYDROPY) | ☐ (SMED:HYDROPY) | ☐ (SMED:HYDROPY) | ☐ (SMED:HYDROPR) | ☐ (SMED:HYDROPR) | ☐ (SMED:HYDROPR) | |
| Other Anti-Sickling Agents | ☐ (SMED:ANTISPY) | ☐ (SMED:ANTISPY) | ☐ (SMED:ANTISPY) | ☐ (SMED:ANTISPR) | ☐ (SMED:ANTISPR) | ☐ (SMED:ANTISPR) | Past year: SMED:ANTISS1<br>Prior to past year: SMED:ANTISS2 |
| Prophylactic Penicillin, other Prophylactic Antibiotics | ☐ (SMED:PROPPY) | ☐ (SMED:PROPPY) | ☐ (SMED:PROPPY) | ☐ (SMED:PROPPR) | ☐ (SMED:PROPPR) | ☐ (SMED:PROPPR) | |
| Desferal | ☐ (SMED:DESFPY) | ☐ (SMED:DESFPY) | ☐ (SMED:DESFPY) | ☐ (SMED:DESFPR) | ☐ (SMED:DESFPR) | ☐ (SMED:DESFPR) | |
| Oral iron chelator (i.e., Exjade/Deferasirox) | ☐ (SMED:IRONPY) | ☐ (SMED:IRONPY) | ☐ (SMED:IRONPY) | ☐ (SMED:IRONPR) | ☐ (SMED:IRONPR) | ☐ (SMED:IRONPR) | |
| Oxygen at home | ☐ (SMED:OXYGPY) | ☐ (SMED:OXYGPY) | ☐ (SMED:OXYGPY) | ☐ (SMED:OXYGPR) | ☐ (SMED:OXYGPR) | ☐ (SMED:OXYGPR) | |
| Antidepressants | ☐ (SMED:ANTIDPY) | ☐ (SMED:ANTIDPY) | ☐ (SMED:ANTIDPY) | ☐ (SMED:ANTIDPR) | ☐ (SMED:ANTIDPR) | ☐ (SMED:ANTIDPR) | Past year: SMED:ANTIDS1<br>Prior to past year: SMED:ANTIDS2 |
| Anticonvulsants | ☐ (SMED:ANTICPY) | ☐ (SMED:ANTICPY) | ☐ (SMED:ANTICPY) | ☐ (SMED:ANTICPR) | ☐ (SMED:ANTICPR) | ☐ (SMED:ANTICPR) | Past year: SMED:ANTICS1<br>Prior to past year: SMED:ANTICS2 |
| Narcotics Daily, 30+ days | ☐ (SMED:NARCPY) | ☐ (SMED:NARCPY) | ☐ (SMED:NARCPY) | ☐ (SMED:NARCPR) | ☐ (SMED:NARCPR) | ☐ (SMED:NARCPR) | |


Submit Query
Cancel
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| Comprehensive Sickle Cell Centers | Medical History Form<br>Part I Transfusion History | Page: {section.pageNumber} |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: TRAN:COMPDA (DD) / TRAN:COMPMO (MMM) / TRAN:COMPYR (YYYY)<br>Form Completed by: TRAN:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Did this patient receive a transfusion *in the past year*?** ☐ (TRAN:TRANPY) Yes ☐ (TRAN:TRANPY) No ☐ (TRAN:TRANPY) Unknown

**If yes, how would you describe this patient's transfusion history *in the past year*?**

Number of transfusions: ☐ (TRAN:TRANHX) 1-5 ☐ (TRAN:TRANHX) 6-20 ☐ (TRAN:TRANHX) 21-99 ☐ (TRAN:TRANHX) 100+

**Did this patient receive a transfusion *prior to the past year*?** ☐ (TRAN:TRANPR) Yes ☐ (TRAN:TRANPR) No ☐ (TRAN:TRANPR) Unknown

**If yes, how would you describe this patient's transfusion history *prior to the past year*?**

Number of transfusions: ☐ (TRAN:TRANPHX) 1-5 ☐ (TRAN:TRANPHX) 6-20 ☐ (TRAN:TRANPHX) 21-99 ☐ (TRAN:TRANPHX) 100+

**Was iron overload *ever* assessed?** ☐ (TRAN:IRONOV) Yes ☐ (TRAN:IRONOV) No ☐ (TRAN:IRONOV) Unknown

**If yes,** enter results of the most recent assessments:

| | Yes | No | Unknown | Result | Date |
|---|---|---|---|---|---|
| Liver Biopsy: | ☐ (TRAN:LIVER) | ☐ (TRAN:LIVER) | ☐ (TRAN:LIVER) | TRAN:LIVRES mg Fe/g Dry Weight | TRAN:LIVRDA / TRAN:LIVRMO / TRAN:LIVRYR DD MMM YYYY |
| Ferritin: | ☐ (TRAN:FERRIT) | ☐ (TRAN:FERRIT) | ☐ (TRAN:FERRIT) | TRAN:FERRES µg/L | TRAN:FERRDA / TRAN:FERRMO / TRAN:FERRYR DD MMM YYYY |
| SQUID: | ☐ (TRAN:SQUID) | ☐ (TRAN:SQUID) | ☐ (TRAN:SQUID) | TRAN:SQUIRES mg Fe/g Dry Weight | TRAN:SQUIDDA / TRAN:SQUIDMO / TRAN:SQUIDYR DD MMM YYYY |

**Did this patient *ever* receive iron chelation therapy?** (i.e., Exjade/Deferasirox)
☐ (TRAN:IRONCH) Yes ☐ (TRAN:IRONCH) No ☐ (TRAN:IRONCH) Unknown

**If yes, check all that apply:**
☐ (TRAN:ORAL) Desferal ☐ (TRAN:IRONTH) Oral (i.e., Exjade/deferasirox) ☐ (TRAN:UNKNOWN) Unknown

**Did this patient receive any transplants *in the past year*?** ☐ (TRAN:TRANYR) Yes ☐ (TRAN:TRANYR) No ☐ (TRAN:TRANYR) Unknown

**Did this patient receive any transplants *prior to the past year*?** ☐ (TRAN:TRANP) Yes ☐ (TRAN:TRANP) No ☐ (TRAN:TRANP) Unknown

**If yes to either question, press the "Add" button to record the following information about each transplant:**

Date of Transplant: TPLN:TPLANDA / TPLN:TPLANMO / TPLN:TPLANYR

Delete Entry

DD MMM YYYY

Site(s): TPLN:TPLANSP

Type of donor:
☐ (TPLN:DONOR) HOA matched
☐ (TPLN:DONOR) Cord blood
☐ (TPLN:DONOR) Other

Type of transplant:
☐ (TPLN:TYPE) Myeloablative
☐ (TPLN:TYPE) Other

Add Entry

Comments for page:
TRAN:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form Part I Selected Diagnostic Tests | Page: {section.pageNumber} |
|---|---|---|
| Collaborative Data Project | Date Form Completed: DIAG:COMPDA / DIAG:COMPMO / DIAG:COMPYR (DD / MMM / YYYY)<br>Form Completed by: DIAG:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Has this patient *ever* had RBC antibodies documented?** ☐ (DIAG:RBCDOC) Yes ☐ (DIAG:RBCDOC) No ☐ (DIAG:RBCDOC) Unknown

*If yes, check all that were present/positive:*

☐ (DIAG:LC) c ☐ (DIAG:UE) E ☐ (DIAG:FYB) Fyb ☐ (DIAG:LK) k ☐ (DIAG:LEB) Leb ☐ (DIAG:COLD) Cold antibody

☐ (DIAG:UC) C ☐ (DIAG:LE) e ☐ (DIAG:JKA) Jka ☐ (DIAG:UK) K ☐ (DIAG:M) M ☐ (DIAG:RBCUNK) Unknown

☐ (DIAG:D) D ☐ (DIAG:FYA) Fya ☐ (DIAG:JKB) Jkb ☐ (DIAG:LEA) Lea ☐ (DIAG:WARM) Warm autoantibody ☐ (DIAG:RBCOTH) Other

**Selected Diagnostic Tests -** Provide information on the most recent diagnostic tests performed on this patient in the ***past year*** and the most recent test performed in the ***2 years prior to the past year*.**

| Test | Performed | | | Test Date | Most Recent Result | | | Comments |
|---|---|---|---|---|---|---|---|---|
| | | | | | Normal | Abnormal | | (reason for test, etc.) |
| | Yes | No | Unk | DD/MMM/YYYY | | | Equivocal | |
| MRI, Head -- in past year | ☐ (DIAG:MRIPY) | ☐ (DIAG:MRIPY) | ☐ (DIAG:MRIPY) | DIAG:MRIPYDA / DIAG:MRIPYMO / DIAG:MRIPYYR | ☐ (DIAG:MRIPYRS) | ☐ (DIAG:MRIPYRS) | ☐ (DIAG:MRIPYRS) | DIAG:MRIPYC |
| **MRI, Head -- in 2 years prior to past year** | ☐ (DIAG:MRI2Y) | ☐ (DIAG:MRI2Y) | ☐ (DIAG:MRI2Y) | DIAG:MRI2YDA / DIAG:MRI2YMO / DIAG:MRI2YYR | ☐ (DIAG:MRI2YRS) | ☐ (DIAG:MRI2YRS) | ☐ (DIAG:MRI2YRS) | DIAG:MRI2YC |
| MRA, Head -- in past year | ☐ (DIAG:MRAPY) | ☐ (DIAG:MRAPY) | ☐ (DIAG:MRAPY) | DIAG:MRAPYDA / DIAG:MRAPYMO / DIAG:MRAPYYR | ☐ (DIAG:MRAPYRS) | ☐ (DIAG:MRAPYRS) | ☐ (DIAG:MRAPYRS) | DIAG:MRAPYC |
| **MRA, Head -- in 2 years prior to past year** | ☐ (DIAG:MRA2Y) | ☐ (DIAG:MRA2Y) | ☐ (DIAG:MRA2Y) | DIAG:MRA2YDA / DIAG:MRA2YMO / DIAG:MRA2YYR | ☐ (DIAG:MRA2YRS) | ☐ (DIAG:MRA2YRS) | ☐ (DIAG:MRA2YRS) | DIAG:MRA2YC |
| Transcranial Doppler (TCD) -- in past year | ☐ (DIAG:TCDPY) | ☐ (DIAG:TCDPY) | ☐ (DIAG:TCDPY) | DIAG:TCDPYDA / DIAG:TCDPYMO / DIAG:TCDPYYR | ☐ (DIAG:TCDPYRS) | ☐ (DIAG:TCDPYRS) | ☐ (DIAG:TCDPYRS) | DIAG:TCDPYC |
| **Transcranial Doppler (TCD) -- in 2 years prior to past year** | ☐ (DIAG:TCD2Y) | ☐ (DIAG:TCD2Y) | ☐ (DIAG:TCD2Y) | DIAG:TCD2YDA / DIAG:TCD2YMO / DIAG:TCD2YYR | ☐ (DIAG:TCD2YRS) | ☐ (DIAG:TCD2YRS) | ☐ (DIAG:TCD2YRS) | DIAG:TCD2YC |
| Echocardiogram -- in past year | ☐ (DIAG:ECHPY) | ☐ (DIAG:ECHPY) | ☐ (DIAG:ECHPY) | DIAG:ECHPYDA / DIAG:ECHPYMO / DIAG:ECHPYYR | ☐ (DIAG:ECHPYRS) | ☐ (DIAG:ECHPYRS) | ☐ (DIAG:ECHPYRS) | DIAG:ECHPYC |
| **Echocardiogram -- in 2 years prior to past year** | ☐ (DIAG:ECH2Y) | ☐ (DIAG:ECH2Y) | ☐ (DIAG:ECH2Y) | DIAG:ECH2YDA / DIAG:ECH2YMO / DIAG:ECH2YYR | ☐ (DIAG:ECH2YRS) | ☐ (DIAG:ECH2YRS) | ☐ (DIAG:ECH2YRS) | DIAG:ECH2YC |
| Pulmonary Function Testing -- in past year | ☐ (DIAG:PFTPY) | ☐ (DIAG:PFTPY) | ☐ (DIAG:PFTPY) | DIAG:PFTPYDA / DIAG:PFTPYMO / DIAG:PFTPYYR | ☐ (DIAG:PFTPYRS) | ☐ (DIAG:PFTPYRS) | ☐ (DIAG:PFTPYRS) | DIAG:PFTPYC |
| **Pulmonary Function Testing -- in 2 years prior to past** | ☐ (DIAG:PFT2Y) | ☐ (DIAG:PFT2Y) | ☐ (DIAG:PFT2Y) | DIAG:PFT2YDA / DIAG:PFT2YMO / DIAG:PFT2YYR | ☐ (DIAG:PFT2YRS) | ☐ (DIAG:PFT2YRS) | ☐ (DIAG:PFT2YRS) | DIAG:PFT2YC |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **year** | | | | | | | | |
| EKG -- in past year | ☐ (DIAG:EKGPY) | ☐ (DIAG:EKGPY) | ☐ (DIAG:EKGPY) | DIAG:EKGPYDA / DIAG:EKGPYMO / DIAG:EKGPYYR | ☐ (DIAG:EKGPYRS) | ☐ (DIAG:EKGPYRS) | ☐ (DIAG:EKGPYRS) | DIAG:EKGPYC |
| **EKG -- in 2 years prior to past year** | ☐ (DIAG:EKG2Y) | ☐ (DIAG:EKG2Y) | ☐ (DIAG:EKG2Y) | DIAG:EKG2YDA / DIAG:EKG2YMO / DIAG:EKG2YYR | ☐ (DIAG:EKG2YRS) | ☐ (DIAG:EKG2YRS) | ☐ (DIAG:EKG2YRS) | DIAG:EKG2YC |

Comments for page:

DIAG:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form Part I Selected Lab Tests | Page: {section.pageNumber} |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: SLAB:COMPDA (DD) / SLAB:COMPMO (MMM) / SLAB:COMPYR (YYYY)<br>Form Completed by: SLAB:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

Please record the most recent blood counts (if available) from the last 2 years. The values MUST be from when the patient was an outpatient and had not been transfused or hospitalized for at least 2 months. The patient should have also not been experiencing any other clinical event that would influence these labs (i.e., parvovirus) at the time the labs were drawn.

**Does this patient have labs recorded during the last 2 years that meet the criteria described above?** ☐ (SLAB:CHTRLAB) Yes ☐ (SLAB:CHTRLAB) No

**If Yes,** record lab values below:

| Test | Most Recent Specimen Date (DD / MMM / YYYY) | Result | Comment |
|---|---|---|---|
| Hgb | SLAB:HGBDA / SLAB:HGBMO / SLAB:HGBYR | SLAB:HGBRS (gm/dL) | SLAB:HGBCM |
| WBC | SLAB:WBCDA / SLAB:WBCMO / SLAB:WBCYR | SLAB:WBCRS ($x10^9$/L) | SLAB:WBCCM |
| Platelet | SLAB:PLATEDA / SLAB:PLATEMO / SLAB:PLATEYR | SLAB:PLATERS ($x10^9$/L) | SLAB:PLATECM |

Comments for page:
SLAB:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form Part I Hospital Admissions | Page: {section.pageNumber} |
|---|---|---|
| Collaborative Data Project | Date Form Completed: HOSQ:COMPDA (DD) / HOSQ:COMPMO (MMM) / HOSQ:COMPYR (YYYY)<br>Form Completed by: HOSQ:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

*List all Hospital Admissions during the **past 2 years**. If possible, identify the primary discharge diagnoses.*

| Date Admitted (DD / MMM / YYYY) | Date Discharged (DD / MMM / YYYY) | Most Important Discharge Diagnoses (up to 3) *Select all that apply* | |
|---|---|---|---|
| HOSP:ADMITDA / HOSP:ADMITMO / HOSP:ADMITYR | HOSP:DISCHDA / HOSP:DISCHMO / HOSP:DISCHYR | HOSP:DDIAG1<br>If Other, specify: HOSP:DDOT1<br>HOSP:DDIAG2<br>If Other, specify: HOSP:DDOT2<br>HOSP:DDIAG3<br>If Other, specify: HOSP:DDOT3 | Delete Admission |

Add Admission

**Do you think admissions not listed above occurred for this patient at other hospitals that are not associated with your center?**

☐ (HOSQ:HOSPOTI) Yes ☐ (HOSQ:HOSPOTI) No ☐ (HOSQ:HOSPOTI) Unknown

Comments for page:

HOSQ:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Medical History Form Part I** | **Page: {section.pageNumber}** |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PROD:COMPDA / PROD:COMPMO / PROD:COMPYR (DD / MMM / YYYY)<br>Form Completed by: PROD:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**For Provider use only:**

Based on social or psychological factors, or clinical attendance or scheduled visit compliance, would you exclude this patient from participation in a clinical trial?

- ☐ (PROD:EXCLUDE) Would exclude, or probably would exclude
- ☐ (PROD:EXCLUDE) Would not exclude, or probably would not exclude
- ☐ (PROD:EXCLUDE) Not sure

Check only one:

- ☐ (PROD:MEDINFO) Information for this medical history was obtained totally from chart abstraction and medical records.
- ☐ (PROD:MEDINFO) Some information was provided by the patient (or parent/guardian of the patient).

  **Please check the pages that include information provided by the patient (or parent/guardian of the patient):** *(check all that apply)*

  - ☐ (PROD:PAGE1) Page 1 specify: PROD:PAGE1SP
  - ☐ (PROD:SURGHX) Surgical History (page 2)
  - ☐ (PROD:MEDCOND) Medical Conditions (pages 3 and 4)
  - ☐ (PROD:SELMED) Selected Medications (page 5)
  - ☐ (PROD:TRANHX) Transfusion History (page 6a)
  - ☐ (PROD:TPLAN) Transplants (page 6b)
  - ☐ (PROD:RBCANTI) RBC antibodies (page 7)
  - ☐ (PROD:DIAGTST) Selected Diagnostic Tests (page 7)
  - ☐ (PROD:LABTST) Selected Lab Tests (page 8)
  - ☐ (PROD:HOSPADM) Hospital Admissions (page 9)

Comments for page:

PROD:COMTXT


Submit Query
Cancel
Form Completion Help
Print

| Comprehensive Sickle Cell Centers | Medical History Form IIA<br>Patient Interview | Pages: 1 - 3 |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: MD2A:COMPDA (DD) / MD2A:COMPMO (MMM) / MD2A:COMPYR (YYYY)<br>Form Completed by: MD2A:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

Was this interview conducted in person or by phone? ☐ (MD2A:INTVW) In person ☐ (MD2A:INTVW) By phone

1. **Which of the following racial groups do you consider yourself a part of?** *(check all that apply)*
   - ☐ (MD2A:INDIAN) American Indian/Alaska Native
   - ☐ (MD2A:ASIAN) Asian
   - ☐ (MD2A:BLACK) Black or African-American
   - ☐ (MD2A:HAWA) Native Hawaiian or other Pacific Islander
   - ☐ (MD2A:WHITE) White
   - ☐ (MD2A:RACOTH) Other, specify MD2A:RACOTHS

2. **What is your ethnicity?** Are you:
   - ☐ (MD2A:ETHNIC) Hispanic or Latino, or
   - ☐ (MD2A:ETHNIC) Not Hispanic or Latino

3a. **How many siblings do you have?** MD2A:SIBLNO

**Of the siblings who share both your biological mother and father:**

3b. How many have SCD? MD2A:SIBWSCD

3c. How many do not have SCD? MD2A:SIBNSCD

4. **What is your current employment status?** Are you:
   - ☐ (MD2A:EMPLOY) Full Time,
   - ☐ (MD2A:EMPLOY) Part Time, or
   - ☐ (MD2A:EMPLOY) Not Employed

5. **What is your current student status?** Are you: ☐ (MD2A:STUSTAT) Full Time,
☐ (MD2A:STUSTAT) Part Time, or
☐ (MD2A:STUSTAT) Not a Student

6. **What is the highest grade of school you have completed, or how many years of college have you completed?** MD2A:HIGHGRD *(Enter 0 for pre-school or less, K for kindergarten, 1-12, 13 = 1 year college, 14 = 2 years college, etc.)*

7. **What is the number of individuals (19 years of age and up) in your household?** MD2A:INDGT19

8. **What is the number of individuals (under 19 years of age) in your household?** MD2A:INDLT19

9. **What type of health insurance do you have?** *(check all that apply)*

☐ (MD2A:PRIVATE) Private ☐ (MD2A:MEDICAR) Medicare ☐ (MD2A:MEDICAI) Medicaid ☐ (MD2A:NONEINS) None ☐ (MD2A:OTHINS) Other
MD2A:HLTHSP

10a. **In the last 5 years, have you received sickle cell-related healthcare from any other center or institution?**

☐ (MD2A:SCHLTH) Yes ☐ (MD2A:SCHLTH) No ☐ (MD2A:SCHLTH) Unknown

. *10b. [If yes]* **Where?** **How many times?**

| | |
|---|---|
| MD2A:SCWHER1 | MD2A:SCTIME1 |
| MD2A:SCWHER2 | MD2A:SCTIME2 |
| MD2A:SCWHER3 | MD2A:SCTIME3 |

11a. **Have you ever received a transfusion?** ☐ (MD2A:TRANS) Yes ☐ (MD2A:TRANS) No ☐ (MD2A:TRANS) Unknown

*11b. [If yes]* How many transfusions? ☐ (MD2A:TRANNO) 1-5 ☐ (MD2A:TRANNO) 6-20 ☐ (MD2A:TRANNO) 21-99 ☐ (MD2A:TRANNO) 100+

12a. **In the past year, have you ever had a headache?** ☐ (MD2A:HEADACH) Yes ☐ (MD2A:HEADACH) No ☐ (MD2A:HEADACH) Unknown

*12b. [If yes]* How many headaches have you had? MD2A:HEAD1

12c. How many of these headaches occurred while you had sickle pain? MD2A:HEAD2 *Put 0 for none*

. 12d. How many of these headaches were not associated with sickle pain, fever/illness or alcohol? MD2A:HEAD3 *Put 0 for none*

13a. **Have you ever gone to a doctor's office, a day hospital, an emergency department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease?**

☐ (MD2A:PAINVIS) Yes ☐ (MD2A:PAINVIS) No ☐ (MD2A:PAINVIS) Unknown

*13b. [If yes]* How many times? ☐ (MD2A:PAINNO) 1-5 ☐ (MD2A:PAINNO) 6-20 ☐ (MD2A:PAINNO) 21-99 ☐ (MD2A:PAINNO) 100+

14. **In the past year, how many times have you come to the doctor's office, the day hospital, Emergency Department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease?** MD2A:SCPAINY *Put 0 for none*

15. **In the past year, how many days of work or school have you missed due to your Sickle Cell Disease?** MD2A:DAYMISS *Put 0 for none*

16. **In the past year, what was the total number of painful episodes due to Sickle Cell Disease for which you were treated solely at home?** MD2A:EPISNO *Put 0 for none*

PI/SC Signature: ☐ (MD2A:PICHECK) Date: MD2A:SIGNDA / MD2A:SIGNMO / MD2A:SIGNYR

DD MMM YYYY

Submit Query | Cancel | Form Completion Help | Print

**For Female Patients:** ☐ (PREG:FPATNA) NA (for males and females not of child-bearing potential)

17. **Are you currently pregnant?** ☐ (PREG:CURPREG) Yes ☐ (PREG:CURPREG) No ☐ (PREG:CURPREG) Unknown

18a. **Have you ever been pregnant (exclude current pregnancy if applicable)?** ☐ (PREG:EVPREG) Yes ☐ (PREG:EVPREG) No ☐ (PREG:EVPREG) Unknown

*[If yes]* How many previous pregnancies have resulted in: *(number)*

18b. PREG:FULLB Full term births

18c. PREG:MISSCAR Miscarriages (spontaneous abortions)

18d. PREG:LIVEB Live Births

18e. PREG:PREMB Premature births

18f. PREG:ABORT Abortions (elective)

18g. PREG:MULTB Multiple Births

18h. PREG:LIVEC Live children at present

*[If 18g is a number other than "0"]* Record the type of multiple birth for each (i.e., "twins"):

Multiple birth 1: PREG:MULTB1

Multiple birth 2: PREG:MULTB2

Multiple birth 3: PREG:MULTB3

Multiple birth 4: PREG:MULTB4

Multiple birth 5: PREG:MULTB5

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form IIA Patient Interview | Page: 4 |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: {COMPDT}<br>Form Completed by: {COMPINT} | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Tobacco Use in the past year**

| | | | | |
|---|---|---|---|---|
| 19. | **Did you use any type of tobacco in the past year?** | ☐ (TOBA:ANYTOB) Yes | ☐ (TOBA:ANYTOB) No | ☐ (TOBA:ANYTOB) Unknown |
| 20a. | **Do you currently use tobacco?** | ☐ (TOBA:CURTOB) Yes | ☐ (TOBA:CURTOB) No | ☐ (TOBA:CURTOB) Unknown |

| | | | | | |
|---|---|---|---|---|---|
| *[If yes]* | 20b. | What is your usual number of **cigarettes?** | TOBA:CIGET | per | TOBA:CIGETFR |
| | 20c. | What is your usual number of **cigars?** | TOBA:CIGAR | per | TOBA:CIGARFR |
| | 20d. | How often do you use **snuff/chew?** | TOBA:SNUF | per | TOBA:SNUFFR |
| | 20e. | How often do you smoke a **pipe?** | TOBA:PIPE | per | TOBA:PIPEFR |

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Medical History Form IIA Patient Interview | Page: 4 |
|---|---|---|
| Collaborative Data Project | Date of Interview: {COMPDT}<br>Form Completed by: {COMPINT} | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Alcohol Use in the past year**

| | | | | |
|---|---|---|---|---|
| 21. | **Did you drink any type of alcohol during the past year?** | ☐ (ALCO:ANYALCO) Yes | ☐ (ALCO:ANYALCO) No | ☐ (ALCO:ANYALCO) Unknown |
| 22a. | **Do you currently drink alcohol?** | ☐ (ALCO:CURALCO) Yes | ☐ (ALCO:CURALCO) No | ☐ (ALCO:CURALCO) Unknown |

| | | | | | |
|---|---|---|---|---|---|
| *[If yes]* | 22b. | What is your usual number of **beers?** | ALCO:BEER | per | ALCO:BEERFR |
| | 22c. | What is your usual number of **glasses of wine ?** | ALCO:WINE | per | ALCO:WINEFR |
| | 22d. | What is your usual number of **other alcoholic drinks ?** | ALCO:DRINK | per | ALCO:DRINKFR |

Submit Query | Cancel | Form Completion Help | Print

23. **Which of these letters best describes your household's yearly income? This includes the total amount of money for all members of your household combined, from all sources including jobs, disability payments or money from the government?**

| | | | | | |
|---|---|---|---|---|---|
| ☐ (INCA:INCOMEQ) | A. Under $4,999 | ☐ (INCA:INCOMEQ) | D. $15,000 - 24,999 | ☐ (INCA:INCOMEQ) | G. $45,000 and over |
| ☐ (INCA:INCOMEQ) | B. $5,000 - 9,999 | ☐ (INCA:INCOMEQ) | E. $25,000 - 34,999 | ☐ (INCA:INCOMEQ) | H. Prefer not to answer |
| ☐ (INCA:INCOMEQ) | C. $10,000 - 14,999 | ☐ (INCA:INCOMEQ) | F. $35,000 - 44,999 | ☐ (INCA:INCOMEQ) | I. Don't know |

Comments for interview pages 1-4:

INCA:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Medical History Form IIB**<br>**Parent (or Accompanying Adult) Interview** | **Pages: 1 - 3** |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: MD2B:COMPDA / MD2B:COMPMO / MD2B:COMPYR<br>DD MMM YYYY<br>Form Completed by: MD2B:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

Who is accompanying this child today? ☐ (MD2B:ACCOMP) Parent ☐ (MD2B:ACCOMP) Guardian ☐ (MD2B:ACCOMP) Other adult relative

Was this interview conducted in person or by phone? ☐ (MD2B:INTVW) In person ☐ (MD2B:INTVW) By phone

1. **Which of the following racial groups do you consider this child a part of?**
   *(check all that apply)*

   ☐ (MD2B:INDIAN) American Indian/Alaska Native
   ☐ (MD2B:ASIAN) Asian
   ☐ (MD2B:BLACK) Black or African-American
   ☐ (MD2B:HAWA) Native Hawaiian or other Pacific Islander
   ☐ (MD2B:WHITE) White
   ☐ (MD2B:RACOTH) Other, specify MD2B:RACOTHS

2. **What is this child's ethnicity?** ☐ (MD2B:ETHNIC) Hispanic or Latino, or
   ☐ (MD2B:ETHNIC) Not Hispanic or Latino

3a. **How many siblings does this child have?** MD2B:SIBLNO

**Of the siblings who share both this child's biological mother and father:**

3b. How many have SCD? MD2B:SIBWSCD

3c. How many do not have SCD? MD2B:SIBNSCD

4. **What is the highest grade of school this child has completed?** MD2B:HIGHGRD *(Enter 0 for pre-school or less, K for kindergarten, 1-12, 13 = 1 year college, 14 = 2 years college, etc.)*

5. **What is the number of individuals (19 years of age and up) in this child's household?** MD2B:INDGT19

6. **What is the number of individuals (under 19 years of age) in this child's household?** MD2B:INDLT19

7. **What type of health insurance does this child have?** *(check all that apply)*

☐ (MD2B:PRIVATE) Private ☐ (MD2B:MEDICAR) Medicare ☐ (MD2B:MEDICAI) Medicaid ☐ (MD2B:NONEINS) None ☐ (MD2B:OTHINS) Other

MD2B:HLTHSP

8a. **In the last 5 years, has this child received sickle cell-related healthcare from any other center or institution?**

☐ (MD2B:SCHLTH) Yes ☐ (MD2B:SCHLTH) No ☐ (MD2B:SCHLTH) Unknown

. *8b. [If yes]* **Where?** **How many times?**

| | |
|---|---|
| MD2B:SCWHER1 | MD2B:SCTIME1 |
| MD2B:SCWHER2 | MD2B:SCTIME2 |
| MD2B:SCWHER3 | MD2B:SCTIME3 |

9a. **Has this child ever received a transfusion?** ☐ (MD2B:TRANS) Yes ☐ (MD2B:TRANS) No ☐ (MD2B:TRANS) Unknown

*9b. [If yes]* How many transfusions? ☐ (MD2B:TRANNO) 1-5 ☐ (MD2B:TRANNO) 6-20 ☐ (MD2B:TRANNO) 21-99 ☐ (MD2B:TRANNO) 100+

10a. **Has this child ever gone to a doctor's office, a day hospital, an emergency department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease?**

☐ (MD2B:SCPAIN) Yes ☐ (MD2B:SCPAIN) No ☐ (MD2B:SCPAIN) Unknown

*10b. [If yes]* How many times? ☐ (MD2B:PAINNO) 1-5 ☐ (MD2B:PAINNO) 6-20 ☐ (MD2B:PAINNO) 21-99 ☐ (MD2B:PAINNO) 100+

11a. **In the past year, has your child ever had a headache?** ☐ (MD2B:HEADACH) Yes ☐ (MD2B:HEADACH) No ☐ (MD2B:HEADACH) Unknown

*11b. [If yes,]* How many headaches has he/she had? MD2B:HEAD1

11c. How many of these headaches occurred while he/she had sickle pain? MD2B:HEAD2 *Put 0 for none*

. 11d. How many of these headaches were not associated with sickle pain, fever/illness or alcohol? MD2B:HEAD3 *Put 0 for none*

12. **In the past year, how many times has this child come to the doctor's office, the day hospital, Emergency Department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease?** MD2B:PAINVIS *Put 0 for none*

13. **In the past year, how many days of school has this child missed due to his/her Sickle Cell Disease?** *Put 0 for none*

MD2B:DAYMISS

14. **In the past year, how many days of school or work have the primary caregiver(s) of this child missed due to this child's Sickle Cell Disease?** MD2B:PDAYMIS *Put 0 for none*

15. **In the past year, what was the total number of painful episodes due to Sickle Cell Disease for which this child was treated solely at home?** MD2B:EPISNO *Put 0 for none*

PI/SC Signature: ☐ (MD2B:PICHECK) Date: MD2B:SIGNDA / MD2B:SIGNMO / MD2B:SIGNYR

DD MMM YYYY

Submit Query | Cancel | Form Completion Help | Print

16. **Which of these letters best describes this child's household's yearly income? This includes the total amount of money for all members of your household combined, from all sources including jobs, disability payments or money from the government?**

| | | | | | |
|---|---|---|---|---|---|
| ☐ (INCB:INCOMEQ) | A. Under $4,999 | ☐ (INCB:INCOMEQ) | D. $15,000 - 24,999 | ☐ (INCB:INCOMEQ) | G. $45,000 and over |
| ☐ (INCB:INCOMEQ) | B. $5,000 - 9,999 | ☐ (INCB:INCOMEQ) | E. $25,000 - 34,999 | ☐ (INCB:INCOMEQ) | H. Prefer not to answer |
| ☐ (INCB:INCOMEQ) | C. $10,000 - 14,999 | ☐ (INCB:INCOMEQ) | F. $35,000 - 44,999 | ☐ (INCB:INCOMEQ) | I. Don't know |

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Medical History Form IIB**<br>**Parent (or Accompanying Adult) Interview** | **Page: 3** |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: {COMPDT}<br>Form Completed by: {COMPINT} | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**For the interviewer:**

17. **Who answered the questions on pages 1 - 3?**

- ☐ (INTV:INTVWRQ) Primarily the patient
- ☐ (INTV:INTVWRQ) Primarily the parent/accompanying adult
- ☐ (INTV:INTVWRQ) Patient and parent/accompanying adult together

Comments for interview pages 1-3:

INTV:COMTXT

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| Comprehensive Sickle Cell Centers | **Pediatric Quality of Life Inventory Parent Report for Toddlers (2-4)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: QPT2:FORMDA (DD) / QPT2:FORMMO (MMM) / QPT2:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has your child had with...***

| **Physical Functioning** *(problems with...)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Walking | ☐ (QPT2:PHYF1) 0 | ☐ (QPT2:PHYF1) 1 | ☐ (QPT2:PHYF1) 2 | ☐ (QPT2:PHYF1) 3 | ☐ (QPT2:PHYF1) 4 |
| 2. Running | ☐ (QPT2:PHYF2) 0 | ☐ (QPT2:PHYF2) 1 | ☐ (QPT2:PHYF2) 2 | ☐ (QPT2:PHYF2) 3 | ☐ (QPT2:PHYF2) 4 |
| 3. Participating in active play or exercise | ☐ (QPT2:PHYF3) 0 | ☐ (QPT2:PHYF3) 1 | ☐ (QPT2:PHYF3) 2 | ☐ (QPT2:PHYF3) 3 | ☐ (QPT2:PHYF3) 4 |
| 4. Lifting something heavy | ☐ (QPT2:PHYF4) 0 | ☐ (QPT2:PHYF4) 1 | ☐ (QPT2:PHYF4) 2 | ☐ (QPT2:PHYF4) 3 | ☐ (QPT2:PHYF4) 4 |
| 5. Bathing | ☐ (QPT2:PHYF5) 0 | ☐ (QPT2:PHYF5) 1 | ☐ (QPT2:PHYF5) 2 | ☐ (QPT2:PHYF5) 3 | ☐ (QPT2:PHYF5) 4 |
| 6. Helping to pick up his or her toys | ☐ (QPT2:PHYF6) 0 | ☐ (QPT2:PHYF6) 1 | ☐ (QPT2:PHYF6) 2 | ☐ (QPT2:PHYF6) 3 | ☐ (QPT2:PHYF6) 4 |
| 7. Having hurts or aches | ☐ (QPT2:PHYF7) 0 | ☐ (QPT2:PHYF7) 1 | ☐ (QPT2:PHYF7) 2 | ☐ (QPT2:PHYF7) 3 | ☐ (QPT2:PHYF7) 4 |
| 8. Low energy level | ☐ (QPT2:PHYF8) 0 | ☐ (QPT2:PHYF8) 1 | ☐ (QPT2:PHYF8) 2 | ☐ (QPT2:PHYF8) 3 | ☐ (QPT2:PHYF8) 4 |

| **Emotional Functioning** *(problems with...)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling afraid or scared | ☐ (QPT2:EMOF1) 0 | ☐ (QPT2:EMOF1) 1 | ☐ (QPT2:EMOF1) 2 | ☐ (QPT2:EMOF1) 3 | ☐ (QPT2:EMOF1) 4 |
| 2. Feeling sad or blue | ☐ (QPT2:EMOF2) 0 | ☐ (QPT2:EMOF2) 1 | ☐ (QPT2:EMOF2) 2 | ☐ (QPT2:EMOF2) 3 | ☐ (QPT2:EMOF2) 4 |
| 3. Feeling angry | ☐ (QPT2:EMOF3) 0 | ☐ (QPT2:EMOF3) 1 | ☐ (QPT2:EMOF3) 2 | ☐ (QPT2:EMOF3) 3 | ☐ (QPT2:EMOF3) 4 |
| 4. Trouble sleeping | ☐ (QPT2:EMOF4) 0 | ☐ (QPT2:EMOF4) 1 | ☐ (QPT2:EMOF4) 2 | ☐ (QPT2:EMOF4) 3 | ☐ (QPT2:EMOF4) 4 |
| 5. Worrying | ☐ (QPT2:EMOF5) 0 | ☐ (QPT2:EMOF5) 1 | ☐ (QPT2:EMOF5) 2 | ☐ (QPT2:EMOF5) 3 | ☐ (QPT2:EMOF5) 4 |

| **Social Functioning** *(problems with...)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Playing with other children | ☐ (QPT2:SOCF1) 0 | ☐ (QPT2:SOCF1) 1 | ☐ (QPT2:SOCF1) 2 | ☐ (QPT2:SOCF1) 3 | ☐ (QPT2:SOCF1) 4 |
| 2. Other kids not wanting to play with him or her | ☐ (QPT2:SOCF2) 0 | ☐ (QPT2:SOCF2) 1 | ☐ (QPT2:SOCF2) 2 | ☐ (QPT2:SOCF2) 3 | ☐ (QPT2:SOCF2) 4 |
| 3. Getting teased by other children | ☐ (QPT2:SOCF3) 0 | ☐ (QPT2:SOCF3) 1 | ☐ (QPT2:SOCF3) 2 | ☐ (QPT2:SOCF3) 3 | ☐ (QPT2:SOCF3) 4 |

| | | | | | |
|---|---|---|---|---|---|
| 4. Not able to do things that other children his or her age can do | ☐ (QPT2:SOCF4) 0 | ☐ (QPT2:SOCF4) 1 | ☐ (QPT2:SOCF4) 2 | ☐ (QPT2:SOCF4) 3 | ☐ (QPT2:SOCF4) 4 |
| 5. Keeping up when playing with other children | ☐ (QPT2:SOCF5) 0 | ☐ (QPT2:SOCF5) 1 | ☐ (QPT2:SOCF5) 2 | ☐ (QPT2:SOCF5) 3 | ☐ (QPT2:SOCF5) 4 |

***Please complete this section if your child attends school or daycare***

| **School Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Doing the same school activities as peers | ☐ (QPT2:SFUN1) 0 | ☐ (QPT2:SFUN1) 1 | ☐ (QPT2:SFUN1) 2 | ☐ (QPT2:SFUN1) 3 | ☐ (QPT2:SFUN1) 4 |
| 2. Missing school/daycare because of not feeling well | ☐ (QPT2:SFUN2) 0 | ☐ (QPT2:SFUN2) 1 | ☐ (QPT2:SFUN2) 2 | ☐ (QPT2:SFUN2) 3 | ☐ (QPT2:SFUN2) 4 |
| 3. Missing school/daycare to go to the doctor or hospital | ☐ (QPT2:SFUN3) 0 | ☐ (QPT2:SFUN3) 1 | ☐ (QPT2:SFUN3) 2 | ☐ (QPT2:SFUN3) 3 | ☐ (QPT2:SFUN3) 4 |

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| Comprehensive Sickle Cell Centers | **Multidimensional Fatigue Scale Parent Report for Toddlers (2-4)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: FPT2:FORMDA (DD) / FPT2:FORMMO (MMM) / FPT2:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for your child...***

| **General Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling tired | ☐ (FPT2:GEN1) 0 | ☐ (FPT2:GEN1) 1 | ☐ (FPT2:GEN1) 2 | ☐ (FPT2:GEN1) 3 | ☐ (FPT2:GEN1) 4 |
| 2. Feeling physically weak (not strong) | ☐ (FPT2:GEN2) 0 | ☐ (FPT2:GEN2) 1 | ☐ (FPT2:GEN2) 2 | ☐ (FPT2:GEN2) 3 | ☐ (FPT2:GEN2) 4 |
| 3. Feeling too tired to do things that he/she likes to do | ☐ (FPT2:GEN3) 0 | ☐ (FPT2:GEN3) 1 | ☐ (FPT2:GEN3) 2 | ☐ (FPT2:GEN3) 3 | ☐ (FPT2:GEN3) 4 |
| 4. Feeling too tired to spend time with his/her friends | ☐ (FPT2:GEN4) 0 | ☐ (FPT2:GEN4) 1 | ☐ (FPT2:GEN4) 2 | ☐ (FPT2:GEN4) 3 | ☐ (FPT2:GEN4) 4 |
| 5. Trouble finishing things | ☐ (FPT2:GEN5) 0 | ☐ (FPT2:GEN5) 1 | ☐ (FPT2:GEN5) 2 | ☐ (FPT2:GEN5) 3 | ☐ (FPT2:GEN5) 4 |
| 6. Trouble starting things | ☐ (FPT2:GEN6) | ☐ (FPT2:GEN6) | ☐ (FPT2:GEN6) | ☐ (FPT2:GEN6) | ☐ (FPT2:GEN6) |

| | 0 | 1 | 2 | 3 | 4 |
|---|---|---|---|---|---|
| **Sleep/Rest Fatigue** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
| 1. Sleeping a lot | ☐ (FPT2:SLEEP1) 0 | ☐ (FPT2:SLEEP1) 1 | ☐ (FPT2:SLEEP1) 2 | ☐ (FPT2:SLEEP1) 3 | ☐ (FPT2:SLEEP1) 4 |
| 2. Difficulty sleeping through the night | ☐ (FPT2:SLEEP2) 0 | ☐ (FPT2:SLEEP2) 1 | ☐ (FPT2:SLEEP2) 2 | ☐ (FPT2:SLEEP2) 3 | ☐ (FPT2:SLEEP2) 4 |
| 3. Feeling tired when he/she wakes up in the morning | ☐ (FPT2:SLEEP3) 0 | ☐ (FPT2:SLEEP3) 1 | ☐ (FPT2:SLEEP3) 2 | ☐ (FPT2:SLEEP3) 3 | ☐ (FPT2:SLEEP3) 4 |
| 4. Resting a lot | ☐ (FPT2:SLEEP4) 0 | ☐ (FPT2:SLEEP4) 1 | ☐ (FPT2:SLEEP4) 2 | ☐ (FPT2:SLEEP4) 3 | ☐ (FPT2:SLEEP4) 4 |
| 5. Taking a lot of naps | ☐ (FPT2:SLEEP5) 0 | ☐ (FPT2:SLEEP5) 1 | ☐ (FPT2:SLEEP5) 2 | ☐ (FPT2:SLEEP5) 3 | ☐ (FPT2:SLEEP5) 4 |
| 6. Spending a lot of time in bed | ☐ (FPT2:SLEEP6) 0 | ☐ (FPT2:SLEEP6) 1 | ☐ (FPT2:SLEEP6) 2 | ☐ (FPT2:SLEEP6) 3 | ☐ (FPT2:SLEEP6) 4 |

| | | | | | |
|---|---|---|---|---|---|
| **Cognitive Fatigue** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
| 1. Difficulty keeping his/her attention on | ☐ (FPT2:COGNI1) 0 | ☐ (FPT2:COGNI1) 1 | ☐ (FPT2:COGNI1) 2 | ☐ (FPT2:COGNI1) 3 | ☐ (FPT2:COGNI1) 4 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | things | | | | | |
| 2. | Difficulty remembering what people tell him/her | ☐ (FPT2:COGNI2) 0 | ☐ (FPT2:COGNI2) 1 | ☐ (FPT2:COGNI2) 2 | ☐ (FPT2:COGNI2) 3 | ☐ (FPT2:COGNI2) 4 |
| 3. | Difficulty remembering what he/she just heard | ☐ (FPT2:COGNI3) 0 | ☐ (FPT2:COGNI3) 1 | ☐ (FPT2:COGNI3) 2 | ☐ (FPT2:COGNI3) 3 | ☐ (FPT2:COGNI3) 4 |
| 4. | Difficulty thinking quickly | ☐ (FPT2:COGNI4) 0 | ☐ (FPT2:COGNI4) 1 | ☐ (FPT2:COGNI4) 2 | ☐ (FPT2:COGNI4) 3 | ☐ (FPT2:COGNI4) 4 |
| 5. | Trouble remembering what he/she was just thinking | ☐ (FPT2:COGNI5) 0 | ☐ (FPT2:COGNI5) 1 | ☐ (FPT2:COGNI5) 2 | ☐ (FPT2:COGNI5) 3 | ☐ (FPT2:COGNI5) 4 |
| 6. | Trouble remembering more than one thing at a time | ☐ (FPT2:COGNI6) 0 | ☐ (FPT2:COGNI6) 1 | ☐ (FPT2:COGNI6) 2 | ☐ (FPT2:COGNI6) 3 | ☐ (FPT2:COGNI6) 4 |

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| Comprehensive Sickle Cell Centers | Healthcare Satisfaction Module Parent Report | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PHSM:FORMDA (DD) / PHSM:FORMMO (MMM) / PHSM:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***How happy are you with...***

| **Information** | Never | Some-times | Often | Almost Always | Always | Not Applicable |
|---|---|---|---|---|---|---|
| 1. How much information was provided to you about your child's diagnosis | ☐ (PHSM:INFO1) 0 | ☐ (PHSM:INFO1) 1 | ☐ (PHSM:INFO1) 2 | ☐ (PHSM:INFO1) 3 | ☐ (PHSM:INFO1) 4 | ☐ (PHSM:INFO1) N/A |
| 2. How much information was provided to you about the treatment and course of your child's health condition | ☐ (PHSM:INFO2) 0 | ☐ (PHSM:INFO2) 1 | ☐ (PHSM:INFO2) 2 | ☐ (PHSM:INFO2) 3 | ☐ (PHSM:INFO2) 4 | ☐ (PHSM:INFO2) N/A |
| 3. How much information was provided to you about the side effects of your child's treatment | ☐ (PHSM:INFO3) 0 | ☐ (PHSM:INFO3) 1 | ☐ (PHSM:INFO3) 2 | ☐ (PHSM:INFO3) 3 | ☐ (PHSM:INFO3) 4 | ☐ (PHSM:INFO3) N/A |
| 4. How soon | ☐ (PHSM:INFO4) 0 | ☐ (PHSM:INFO4) 1 | ☐ (PHSM:INFO4) 2 | ☐ (PHSM:INFO4) 3 | ☐ (PHSM:INFO4) 4 | ☐ (PHSM:INFO4) |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | information was given to you about your child's test results | | | | | | N/A |
| 5. | How often you are updated about your child's health | ☐ (PHSM:INFO5) 0 | ☐ (PHSM:INFO5) 1 | ☐ (PHSM:INFO5) 2 | ☐ (PHSM:INFO5) 3 | ☐ (PHSM:INFO5) 4 | ☐ (PHSM:INFO5) N/A |

| **Inclusion of Family** | | Never | Some-times | Often | Almost Always | Always | Not Applicable |
|---|---|---|---|---|---|---|---|
| 1. | The sensitivity shown to you and your family during your child's treatment | ☐ (PHSM:INCFAM1) 0 | ☐ (PHSM:INCFAM1) 1 | ☐ (PHSM:INCFAM1) 2 | ☐ (PHSM:INCFAM1) 3 | ☐ (PHSM:INCFAM1) 4 | ☐ (PHSM:INCFAM1) N/A |
| 2. | The willingness to answer questions that you and your family may have | ☐ (PHSM:INCFAM2) 0 | ☐ (PHSM:INCFAM2) 1 | ☐ (PHSM:INCFAM2) 2 | ☐ (PHSM:INCFAM2) 3 | ☐ (PHSM:INCFAM2) 4 | ☐ (PHSM:INCFAM2) N/A |
| 3. | The effort to include your family in discussion of your child's care and other information about your child's health condition | ☐ (PHSM:INCFAM3) 0 | ☐ (PHSM:INCFAM3) 1 | ☐ (PHSM:INCFAM3) 2 | ☐ (PHSM:INCFAM3) 3 | ☐ (PHSM:INCFAM3) 4 | ☐ (PHSM:INCFAM3) N/A |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 4. | How much time the staff gave you to ask any questions you may have had about your child's health condition and treatment | ☐ (PHSM:INCFAM4) 0 | ☐ (PHSM:INCFAM4) 1 | ☐ (PHSM:INCFAM4) 2 | ☐ (PHSM:INCFAM4) 3 | ☐ (PHSM:INCFAM4) 4 | ☐ (PHSM:INCFAM4) N/A |

| **Communication** | | Never | Some-times | Often | Almost Always | Always | Not Applicable |
|---|---|---|---|---|---|---|---|
| 1. | How well the staff explained your child's condition and treatment to **your child** in a way that she/he could understand | ☐ (PHSM:COMM1) 0 | ☐ (PHSM:COMM1) 1 | ☐ (PHSM:COMM1) 2 | ☐ (PHSM:COMM1) 3 | ☐ (PHSM:COMM1) 4 | ☐ (PHSM:COMM1) N/A |
| 2. | The time taken to explain your child's health condition and treatment to **you** in a way you could understand | ☐ (PHSM:COMM2) 0 | ☐ (PHSM:COMM2) 1 | ☐ (PHSM:COMM2) 2 | ☐ (PHSM:COMM2) 3 | ☐ (PHSM:COMM2) 4 | ☐ (PHSM:COMM2) N/A |
| 3. | How well the staff listens to you and your concerns | ☐ (PHSM:COMM3) 0 | ☐ (PHSM:COMM3) 1 | ☐ (PHSM:COMM3) 2 | ☐ (PHSM:COMM3) 3 | ☐ (PHSM:COMM3) 4 | ☐ (PHSM:COMM3) N/A |
| 4. | The preparation provided for **you** about what to expect during tests and procedures | ☐ (PHSM:COMM4) 0 | ☐ (PHSM:COMM4) 1 | ☐ (PHSM:COMM4) 2 | ☐ (PHSM:COMM4) 3 | ☐ (PHSM:COMM4) 4 | ☐ (PHSM:COMM4) N/A |
| 5. | The preparation provided for **your** | ☐ (PHSM:COMM5) 0 | ☐ (PHSM:COMM5) 1 | ☐ (PHSM:COMM5) 2 | ☐ (PHSM:COMM5) 3 | ☐ (PHSM:COMM5) 4 | ☐ (PHSM:COMM5) N/A |

**child** about what to expect during tests and procedures

| **Technical Skills** | Never | Some-times | Often | Almost Always | Always | Not Applicable |
|---|---|---|---|---|---|---|
| 1. How well the staff responds to your child's needs | ☐ (PHSM:SKILL1) 0 | ☐ (PHSM:SKILL1) 1 | ☐ (PHSM:SKILL1) 2 | ☐ (PHSM:SKILL1) 3 | ☐ (PHSM:SKILL1) 4 | ☐ (PHSM:SKILL1) N/A |
| 2. Efforts to keep your child comfortable and as pain-free as possible | ☐ (PHSM:SKILL2) 0 | ☐ (PHSM:SKILL2) 1 | ☐ (PHSM:SKILL2) 2 | ☐ (PHSM:SKILL2) 3 | ☐ (PHSM:SKILL2) 4 | ☐ (PHSM:SKILL2) N/A |
| 3. How much time the staff took to help you with your child coming back home | ☐ (PHSM:SKILL3) 0 | ☐ (PHSM:SKILL3) 1 | ☐ (PHSM:SKILL3) 2 | ☐ (PHSM:SKILL3) 3 | ☐ (PHSM:SKILL3) 4 | ☐ (PHSM:SKILL3) N/A |

| **Emotional Needs** | Never | Some-times | Often | Almost Always | Always | Not Applicable |
|---|---|---|---|---|---|---|
| 1. The amount of time given to your child to play, talk about his/her feelings, and any questions she/he may have | ☐ (PHSM:EMOT1) 0 | ☐ (PHSM:EMOT1) 1 | ☐ (PHSM:EMOT1) 2 | ☐ (PHSM:EMOT1) 3 | ☐ (PHSM:EMOT1) 4 | ☐ (PHSM:EMOT1) N/A |
| 2. The amount of time spent helping your child with going back to school | ☐ (PHSM:EMOT2) 0 | ☐ (PHSM:EMOT2) 1 | ☐ (PHSM:EMOT2) 2 | ☐ (PHSM:EMOT2) 3 | ☐ (PHSM:EMOT2) 4 | ☐ (PHSM:EMOT2) N/A |
| 3. The amount of time spent attending to **your child's** emotional needs | ☐ (PHSM:EMOT3) 0 | ☐ (PHSM:EMOT3) 1 | ☐ (PHSM:EMOT3) 2 | ☐ (PHSM:EMOT3) 3 | ☐ (PHSM:EMOT3) 4 | ☐ (PHSM:EMOT3) N/A |
| 4. The amount of time spent attending to | ☐ (PHSM:EMOT4) 0 | ☐ (PHSM:EMOT4) 1 | ☐ (PHSM:EMOT4) 2 | ☐ (PHSM:EMOT4) 3 | ☐ (PHSM:EMOT4) 4 | ☐ (PHSM:EMOT4) N/A |

**your** emotional needs

| **Overall Satisfaction** | Never | Some-times | Often | Almost Always | Always | Not Applicable |
|---|---|---|---|---|---|---|
| 1. The overall care your child is receiving | ☐ (PHSM:SATIS1) 0 | ☐ (PHSM:SATIS1) 1 | ☐ (PHSM:SATIS1) 2 | ☐ (PHSM:SATIS1) 3 | ☐ (PHSM:SATIS1) 4 | ☐ (PHSM:SATIS1) N/A |
| 2. How friendly and helpful the staff is | ☐ (PHSM:SATIS2) 0 | ☐ (PHSM:SATIS2) 1 | ☐ (PHSM:SATIS2) 2 | ☐ (PHSM:SATIS2) 3 | ☐ (PHSM:SATIS2) 4 | ☐ (PHSM:SATIS2) N/A |
| 3. The way your child is treated at the hospital | ☐ (PHSM:SATIS3) 0 | ☐ (PHSM:SATIS3) 1 | ☐ (PHSM:SATIS3) 2 | ☐ (PHSM:SATIS3) 3 | ☐ (PHSM:SATIS3) 4 | ☐ (PHSM:SATIS3) N/A |

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| Comprehensive Sickle Cell Centers | **Pediatric Quality of Life Inventory Young Child Report (5-7)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: QYC5:FORMDA / QYC5:FORMMO / QYC5:FORMYR (DD / MMM / YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this has been for you.***

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

| **Physical Functioning *(problems with...)*** | | Not at all | Some-times | A lot |
|---|---|---|---|---|
| 1. | Is it hard for you to walk | ☐ (QYC5:PHYFC1) 0 | ☐ (QYC5:PHYFC1) 2 | ☐ (QYC5:PHYFC1) 4 |
| 2. | Is it hard for you to run | ☐ (QYC5:PHYFC2) 0 | ☐ (QYC5:PHYFC2) 2 | ☐ (QYC5:PHYFC2) 4 |
| 3. | Is it hard for you to play sports or exercise | ☐ (QYC5:PHYFC3) 0 | ☐ (QYC5:PHYFC3) 2 | ☐ (QYC5:PHYFC3) 4 |
| 4. | Is it hard for you to pick up big things | ☐ (QYC5:PHYFC4) 0 | ☐ (QYC5:PHYFC4) 2 | ☐ (QYC5:PHYFC4) 4 |
| 5. | Is it hard for you to take a bath or shower | ☐ (QYC5:PHYFC5) 0 | ☐ (QYC5:PHYFC5) 2 | ☐ (QYC5:PHYFC5) 4 |
| 6. | Is it hard for you to do chores (like pick up your toys) | ☐ (QYC5:PHYFC6) 0 | ☐ (QYC5:PHYFC6) 2 | ☐ (QYC5:PHYFC6) 4 |
| 7. | Do you have hurts or aches<br>(***Where?*** QYC5:PHYCS) | ☐ (QYC5:PHYFC7) 0 | ☐ (QYC5:PHYFC7) 2 | ☐ (QYC5:PHYFC7) 4 |
| 8. | Do you ever feel too tired to play | ☐ (QYC5:PHYFC8) 0 | ☐ (QYC5:PHYFC8) 2 | ☐ (QYC5:PHYFC8) 4 |

***Remember, tell me how much of a problem this has been for you for the last few weeks.***

| **Emotional Functioning *(problems with...)*** | | Not at all | Some-times | A lot |
|---|---|---|---|---|
| 1. | Do you feel scared | ☐ (QYC5:EMOFC1) 0 | ☐ (QYC5:EMOFC1) 2 | ☐ (QYC5:EMOFC1) 4 |
| 2. | Do you feel sad | ☐ (QYC5:EMOFC2) 0 | ☐ (QYC5:EMOFC2) 2 | ☐ (QYC5:EMOFC2) 4 |
| 3. | Do you feel mad | ☐ (QYC5:EMOFC3) 0 | ☐ (QYC5:EMOFC3) 2 | ☐ (QYC5:EMOFC3) 4 |
| 4. | Do you have trouble sleeping | ☐ (QYC5:EMOFC4) 0 | ☐ (QYC5:EMOFC4) 2 | ☐ (QYC5:EMOFC4) 4 |
| 5. | Do worry about what will happen to you | ☐ (QYC5:EMOFC5) 0 | ☐ (QYC5:EMOFC5) 2 | ☐ (QYC5:EMOFC5) 4 |

| **Social Functioning *(problems with...)*** | | Not at all | Some-times | A lot |
|---|---|---|---|---|
| 1. | Is it hard for you to get along with other kids | ☐ (QYC5:SOCFC1) 0 | ☐ (QYC5:SOCFC1) 2 | ☐ (QYC5:SOCFC1) 4 |
| 2. | Do other kids say they do not want to play with you | ☐ (QYC5:SOCFC2) 0 | ☐ (QYC5:SOCFC2) 2 | ☐ (QYC5:SOCFC2) 4 |
| 3. | Do other kids tease you | ☐ (QYC5:SOCFC3) 0 | ☐ (QYC5:SOCFC3) 2 | ☐ (QYC5:SOCFC3) 4 |
| 4. | Can other kids do things that you cannot do | ☐ (QYC5:SOCFC4) 0 | ☐ (QYC5:SOCFC4) 2 | ☐ (QYC5:SOCFC4) 4 |

| | | | | |
|---|---|---|---|---|
| 5. | Is it hard for you to keep up when you play with other kids | ☐ (QYC5:SOCFC5) 0 | ☐ (QYC5:SOCFC5) 2 | ☐ (QYC5:SOCFC5) 4 |

| **School Functioning *(problems with...)*** | | Not at all | Some-times | A lot |
|---|---|---|---|---|
| 1. | Is it hard for you to pay attention in school | ☐ (QYC5:SCHFC1) 0 | ☐ (QYC5:SCHFC1) 2 | ☐ (QYC5:SCHFC1) 4 |
| 2. | Do you forget things | ☐ (QYC5:SCHFC2) 0 | ☐ (QYC5:SCHFC2) 2 | ☐ (QYC5:SCHFC2) 4 |
| 3. | Is it hard for you to keep up with schoolwork | ☐ (QYC5:SCHFC3) 0 | ☐ (QYC5:SCHFC3) 2 | ☐ (QYC5:SCHFC3) 4 |
| 4. | Do you miss school because of not feeling good | ☐ (QYC5:SCHFC4) 0 | ☐ (QYC5:SCHFC4) 2 | ☐ (QYC5:SCHFC4) 4 |
| 5. | Do you miss school because you have to go to the doctor's or hospital | ☐ (QYC5:SCHFC5) 0 | ☐ (QYC5:SCHFC5) 2 | ☐ (QYC5:SCHFC5) 4 |

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| Comprehensive Sickle Cell Centers | **Pediatric Quality of Life Inventory**<br>**Parent Report for Young Child (5-7)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: QPY5:FORMDA / QPY5:FORMMO / QPY5:FORMYR<br>DD MMM YYYY | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has your child had with...***

| **Physical Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Walking more than one block | ☐ (QPY5:PHYFP1) 0 | ☐ (QPY5:PHYFP1) 1 | ☐ (QPY5:PHYFP1) 2 | ☐ (QPY5:PHYFP1) 3 | ☐ (QPY5:PHYFP1) 4 |
| 2. Running | ☐ (QPY5:PHYFP2) 0 | ☐ (QPY5:PHYFP2) 1 | ☐ (QPY5:PHYFP2) 2 | ☐ (QPY5:PHYFP2) 3 | ☐ (QPY5:PHYFP2) 4 |
| 3. Participating in sports activity or exercise | ☐ (QPY5:PHYFP3) 0 | ☐ (QPY5:PHYFP3) 1 | ☐ (QPY5:PHYFP3) 2 | ☐ (QPY5:PHYFP3) 3 | ☐ (QPY5:PHYFP3) 4 |
| 4. Lifting something heavy | ☐ (QPY5:PHYFP4) 0 | ☐ (QPY5:PHYFP4) 1 | ☐ (QPY5:PHYFP4) 2 | ☐ (QPY5:PHYFP4) 3 | ☐ (QPY5:PHYFP4) 4 |
| 5. Taking a bath or shower by him or herself | ☐ (QPY5:PHYFP5) 0 | ☐ (QPY5:PHYFP5) 1 | ☐ (QPY5:PHYFP5) 2 | ☐ (QPY5:PHYFP5) 3 | ☐ (QPY5:PHYFP5) 4 |
| 6. Doing chores, like picking up his or her toys | ☐ (QPY5:PHYFP6) 0 | ☐ (QPY5:PHYFP6) 1 | ☐ (QPY5:PHYFP6) 2 | ☐ (QPY5:PHYFP6) 3 | ☐ (QPY5:PHYFP6) 4 |
| 7. Having hurts or aches | ☐ (QPY5:PHYFP7) 0 | ☐ (QPY5:PHYFP7) 1 | ☐ (QPY5:PHYFP7) 2 | ☐ (QPY5:PHYFP7) 3 | ☐ (QPY5:PHYFP7) 4 |
| 8. Low energy level | ☐ (QPY5:PHYFP8) 0 | ☐ (QPY5:PHYFP8) 1 | ☐ (QPY5:PHYFP8) 2 | ☐ (QPY5:PHYFP8) 3 | ☐ (QPY5:PHYFP8) 4 |

| **Emotional Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling afraid or scared | ☐ (QPY5:EMOFP1) 0 | ☐ (QPY5:EMOFP1) 1 | ☐ (QPY5:EMOFP1) 2 | ☐ (QPY5:EMOFP1) 3 | ☐ (QPY5:EMOFP1) 4 |
| 2. Feeling sad or blue | ☐ (QPY5:EMOFP2) 0 | ☐ (QPY5:EMOFP2) 1 | ☐ (QPY5:EMOFP2) 2 | ☐ (QPY5:EMOFP2) 3 | ☐ (QPY5:EMOFP2) 4 |
| 3. Feeling angry | ☐ (QPY5:EMOFP3) 0 | ☐ (QPY5:EMOFP3) 1 | ☐ (QPY5:EMOFP3) 2 | ☐ (QPY5:EMOFP3) 3 | ☐ (QPY5:EMOFP3) 4 |
| 4. Trouble sleeping | ☐ (QPY5:EMOFP4) 0 | ☐ (QPY5:EMOFP4) 1 | ☐ (QPY5:EMOFP4) 2 | ☐ (QPY5:EMOFP4) 3 | ☐ (QPY5:EMOFP4) 4 |
| 5. Worrying about what will happen to him or her | ☐ (QPY5:EMOFP5) 0 | ☐ (QPY5:EMOFP5) 1 | ☐ (QPY5:EMOFP5) 2 | ☐ (QPY5:EMOFP5) 3 | ☐ (QPY5:EMOFP5) 4 |

| **Social Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Getting along with other children | ☐ (QPY5:SOCFP1) 0 | ☐ (QPY5:SOCFP1) 1 | ☐ (QPY5:SOCFP1) 2 | ☐ (QPY5:SOCFP1) 3 | ☐ (QPY5:SOCFP1) 4 |
| 2. Other kids not wanting to be his or her friend | ☐ (QPY5:SOCFP2) 0 | ☐ (QPY5:SOCFP2) 1 | ☐ (QPY5:SOCFP2) 2 | ☐ (QPY5:SOCFP2) 3 | ☐ (QPY5:SOCFP2) 4 |
| 3. Getting teased by other children | ☐ (QPY5:SOCFP3) 0 | ☐ (QPY5:SOCFP3) 1 | ☐ (QPY5:SOCFP3) 2 | ☐ (QPY5:SOCFP3) 3 | ☐ (QPY5:SOCFP3) 4 |
| 4. Not able to do things that other children his or her age can do | ☐ (QPY5:SOCFP4) 0 | ☐ (QPY5:SOCFP4) 1 | ☐ (QPY5:SOCFP4) 2 | ☐ (QPY5:SOCFP4) 3 | ☐ (QPY5:SOCFP4) 4 |
| 5. Keeping up when playing with other children | ☐ (QPY5:SOCFP5) 0 | ☐ (QPY5:SOCFP5) 1 | ☐ (QPY5:SOCFP5) 2 | ☐ (QPY5:SOCFP5) 3 | ☐ (QPY5:SOCFP5) 4 |

| **School Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Paying attention in class | ☐ (QPY5:SCHFP1) 0 | ☐ (QPY5:SCHFP1) 1 | ☐ (QPY5:SCHFP1) 2 | ☐ (QPY5:SCHFP1) 3 | ☐ (QPY5:SCHFP1) 4 |
| 2. Forgetting things | ☐ (QPY5:SCHFP2) 0 | ☐ (QPY5:SCHFP2) 1 | ☐ (QPY5:SCHFP2) 2 | ☐ (QPY5:SCHFP2) 3 | ☐ (QPY5:SCHFP2) 4 |
| 3. Keeping up with school activities | ☐ (QPY5:SCHFP3) 0 | ☐ (QPY5:SCHFP3) 1 | ☐ (QPY5:SCHFP3) 2 | ☐ (QPY5:SCHFP3) 3 | ☐ (QPY5:SCHFP3) 4 |
| 4. Missing school because of not feeling well | ☐ (QPY5:SCHFP4) 0 | ☐ (QPY5:SCHFP4) 1 | ☐ (QPY5:SCHFP4) 2 | ☐ (QPY5:SCHFP4) 3 | ☐ (QPY5:SCHFP4) 4 |
| 5. Missing school to go to the doctor or hospital | ☐ (QPY5:SCHFP5) 0 | ☐ (QPY5:SCHFP5) 1 | ☐ (QPY5:SCHFP5) 2 | ☐ (QPY5:SCHFP5) 3 | ☐ (QPY5:SCHFP5) 4 |

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| Comprehensive Sickle Cell Centers | **Multidimensional Fatigue Scale Young Child Report (5-7)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: FCY5:FORMDA (DD) / FCY5:FORMMO (MMM) / FCY5:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.***

**After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.**

| **General Fatigue *(problems with...)*** | Not At All | Sometimes | A lot |
|---|---|---|---|
| 1. Do you feel tired | ☐ (FCY5:GEN1) 0 | ☐ (FCY5:GEN1) 2 | ☐ (FCY5:GEN1) 4 |
| 2. Do you feel physically weak (not strong) | ☐ (FCY5:GEN2) 0 | ☐ (FCY5:GEN2) 2 | ☐ (FCY5:GEN2) 4 |
| 3. Do you feel too tired to do things that you like to do | ☐ (FCY5:GEN3) 0 | ☐ (FCY5:GEN3) 2 | ☐ (FCY5:GEN3) 4 |
| 4. Do you feel too tired to spend time with your friends | ☐ (FCY5:GEN4) 0 | ☐ (FCY5:GEN4) 2 | ☐ (FCY5:GEN4) 4 |
| 5. Do you have trouble finishing things | ☐ (FCY5:GEN5) 0 | ☐ (FCY5:GEN5) 2 | ☐ (FCY5:GEN5) 4 |
| 6. Do you have trouble starting things | ☐ (FCY5:GEN6) 0 | ☐ (FCY5:GEN6) 2 | ☐ (FCY5:GEN6) 4 |

| **Sleep/Rest Fatigue *(problems with...)*** | Not At All | Sometimes | A lot |
|---|---|---|---|
| 1. Do you sleep a lot | ☐ (FCY5:SLEEP1) 0 | ☐ (FCY5:SLEEP1) 2 | ☐ (FCY5:SLEEP1) 4 |
| 2. Is it hard for you to sleep through the night | ☐ (FCY5:SLEEP2) 0 | ☐ (FCY5:SLEEP2) 2 | ☐ (FCY5:SLEEP2) 4 |
| 3. Do you feel tired when you wake up in the morning | ☐ (FCY5:SLEEP3) 0 | ☐ (FCY5:SLEEP3) 2 | ☐ (FCY5:SLEEP3) 4 |
| 4. Do you rest a lot | ☐ (FCY5:SLEEP4) 0 | ☐ (FCY5:SLEEP4) 2 | ☐ (FCY5:SLEEP4) 4 |
| 5. Do you take a lot of naps | ☐ (FCY5:SLEEP5) 0 | ☐ (FCY5:SLEEP5) 2 | ☐ (FCY5:SLEEP5) 4 |
| 6. Do you spend a lot of time in bed | ☐ (FCY5:SLEEP6) 0 | ☐ (FCY5:SLEEP6) 2 | ☐ (FCY5:SLEEP6) 4 |

| **Cognitive Fatigue *(problems with...)*** | Not At All | Sometimes | A lot |
|---|---|---|---|
| 1. Is it hard for you to keep your attention on things | ☐ (FCY5:COGNI1) 0 | ☐ (FCY5:COGNI1) 2 | ☐ (FCY5:COGNI1) 4 |

| | | | | |
|---|---|---|---|---|
| 2. | Is it hard for you to remember what people tell you | ☐ (FCY5:COGNI2) 0 | ☐ (FCY5:COGNI2) 2 | ☐ (FCY5:COGNI2) 4 |
| 3. | Is it hard for you to remember what you just heard | ☐ (FCY5:COGNI3) 0 | ☐ (FCY5:COGNI3) 2 | ☐ (FCY5:COGNI3) 4 |
| 4. | Is it hard for you to think quickly | ☐ (FCY5:COGNI4) 0 | ☐ (FCY5:COGNI4) 2 | ☐ (FCY5:COGNI4) 4 |
| 5. | Do you have trouble remembering what you were just thinking | ☐ (FCY5:COGNI5) 0 | ☐ (FCY5:COGNI5) 2 | ☐ (FCY5:COGNI5) 4 |
| 6. | Do you have trouble remembering more than one thing at a time | ☐ (FCY5:COGNI6) 0 | ☐ (FCY5:COGNI6) 2 | ☐ (FCY5:COGNI6) 4 |

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| Comprehensive Sickle Cell Centers | **Multidimensional Fatigue Scale Parent Report for Young Child (5-7)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: FPY5:FORMDA (DD) / FPY5:FORMMO (MMM) / FPY5:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for your child...***

| **General Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling tired | ☐ (FPY5:GEN1) 0 | ☐ (FPY5:GEN1) 1 | ☐ (FPY5:GEN1) 2 | ☐ (FPY5:GEN1) 3 | ☐ (FPY5:GEN1) 4 |
| 2. Feeling physically weak (not strong) | ☐ (FPY5:GEN2) 0 | ☐ (FPY5:GEN2) 1 | ☐ (FPY5:GEN2) 2 | ☐ (FPY5:GEN2) 3 | ☐ (FPY5:GEN2) 4 |
| 3. Feeling too tired to do things that he/she likes to do | ☐ (FPY5:GEN3) 0 | ☐ (FPY5:GEN3) 1 | ☐ (FPY5:GEN3) 2 | ☐ (FPY5:GEN3) 3 | ☐ (FPY5:GEN3) 4 |
| 4. Feeling too tired to spend time with his/her friends | ☐ (FPY5:GEN4) 0 | ☐ (FPY5:GEN4) 1 | ☐ (FPY5:GEN4) 2 | ☐ (FPY5:GEN4) 3 | ☐ (FPY5:GEN4) 4 |
| 5. Trouble finishing things | ☐ (FPY5:GEN5) 0 | ☐ (FPY5:GEN5) 1 | ☐ (FPY5:GEN5) 2 | ☐ (FPY5:GEN5) 3 | ☐ (FPY5:GEN5) 4 |
| 6. Trouble starting things | ☐ (FPY5:GEN6) 0 | ☐ (FPY5:GEN6) 1 | ☐ (FPY5:GEN6) 2 | ☐ (FPY5:GEN6) 3 | ☐ (FPY5:GEN6) 4 |

| **Sleep/Rest Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Sleeping a lot | ☐ (FPY5:SLEEP1) 0 | ☐ (FPY5:SLEEP1) 1 | ☐ (FPY5:SLEEP1) 2 | ☐ (FPY5:SLEEP1) 3 | ☐ (FPY5:SLEEP1) 4 |
| 2. Difficulty sleeping through the night | ☐ (FPY5:SLEEP2) 0 | ☐ (FPY5:SLEEP2) 1 | ☐ (FPY5:SLEEP2) 2 | ☐ (FPY5:SLEEP2) 3 | ☐ (FPY5:SLEEP2) 4 |
| 3. Feeling tired when he/she wakes up in the morning | ☐ (FPY5:SLEEP3) 0 | ☐ (FPY5:SLEEP3) 1 | ☐ (FPY5:SLEEP3) 2 | ☐ (FPY5:SLEEP3) 3 | ☐ (FPY5:SLEEP3) 4 |
| 4. Resting a lot | ☐ (FPY5:SLEEP4) 0 | ☐ (FPY5:SLEEP4) 1 | ☐ (FPY5:SLEEP4) 2 | ☐ (FPY5:SLEEP4) 3 | ☐ (FPY5:SLEEP4) 4 |
| 5. Taking a lot of naps | ☐ (FPY5:SLEEP5) 0 | ☐ (FPY5:SLEEP5) 1 | ☐ (FPY5:SLEEP5) 2 | ☐ (FPY5:SLEEP5) 3 | ☐ (FPY5:SLEEP5) 4 |
| 6. Spending a lot of time in bed | ☐ (FPY5:SLEEP6) 0 | ☐ (FPY5:SLEEP6) 1 | ☐ (FPY5:SLEEP6) 2 | ☐ (FPY5:SLEEP6) 3 | ☐ (FPY5:SLEEP6) 4 |

| **Cognitive Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty keeping his/her attention on things | ☐ (FPY5:COGNI1) 0 | ☐ (FPY5:COGNI1) 1 | ☐ (FPY5:COGNI1) 2 | ☐ (FPY5:COGNI1) 3 | ☐ (FPY5:COGNI1) 4 |
| 2. Difficulty | ☐ (FPY5:COGNI2) | ☐ (FPY5:COGNI2) | ☐ (FPY5:COGNI2) | ☐ (FPY5:COGNI2) | ☐ (FPY5:COGNI2) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | remembering what people tell him/her | 0 | 1 | 2 | 3 | 4 |
| 3. | Difficulty remembering what he/she just heard | ☐ (FPY5:COGNI3) 0 | ☐ (FPY5:COGNI3) 1 | ☐ (FPY5:COGNI3) 2 | ☐ (FPY5:COGNI3) 3 | ☐ (FPY5:COGNI3) 4 |
| 4. | Difficulty thinking quickly | ☐ (FPY5:COGNI4) 0 | ☐ (FPY5:COGNI4) 1 | ☐ (FPY5:COGNI4) 2 | ☐ (FPY5:COGNI4) 3 | ☐ (FPY5:COGNI4) 4 |
| 5. | Trouble remembering what he/she was just thinking | ☐ (FPY5:COGNI5) 0 | ☐ (FPY5:COGNI5) 1 | ☐ (FPY5:COGNI5) 2 | ☐ (FPY5:COGNI5) 3 | ☐ (FPY5:COGNI5) 4 |
| 6. | Trouble remembering more than one thing at a time | ☐ (FPY5:COGNI6) 0 | ☐ (FPY5:COGNI6) 1 | ☐ (FPY5:COGNI6) 2 | ☐ (FPY5:COGNI6) 3 | ☐ (FPY5:COGNI6) 4 |

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| Comprehensive Sickle Cell Centers | **Pediatric Pain Questionnaire**<br>**Young Child Form (5-7)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PQC5:FORMDA / PQC5:FORMMO / PQC5:FORMYR<br>DD MMM YYYY | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

## Young Child Form (5-7)

What words would you use to describe your pain or hurt?

PQC5:PAINWRD

Using a metric ruler, measure the distance of the subject's mark from the left-hand anchor on the line of the paper form completed by the patient. In the box below, enter the number in millimeters. Measure to the nearest whole millimeter. A mark drawn exactly on the left-hand anchor (No pain) should be entered as 0 and a mark drawn exactly on the right-hand anchor should be entered as 100 (Severe Pain).

Now: PQC5:PAINNOW

This Week: PQC5:PAINWK

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Pediatric Pain Questionnaire**<br>**Parent of Young Child Form (5-7)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PQP5:FORMDA / PQP5:FORMMO / PQP5:FORMYR<br>DD MMM YYYY | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

What words would you use to describe your child's pain or hurt?

PQP5:PAINWRD

Using a metric ruler, measure the distance of the parent's mark from the left-hand anchor on the line of the paper form completed by the parent. In the box below, enter the number in millimeters. Measure to the nearest whole millimeter. A mark drawn exactly on the left-hand anchor (No pain) should be entered as 0 and a mark drawn exactly on the right-hand anchor should be entered as 100 (Severe Pain).

Now: PQP5:PAINNOW

Past Week: PQP5:PAINWK

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Pediatric Quality of Life Inventory Child Report (8-12)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: QCR8:FORMDA (DD) / QCR8:FORMMO (MMM) / QCR8:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for you...***

| **About My Health and Activities** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Is it hard for me to walk more than one block | ☐ (QCR8:PHYFC1) 0 | ☐ (QCR8:PHYFC1) 1 | ☐ (QCR8:PHYFC1) 2 | ☐ (QCR8:PHYFC1) 3 | ☐ (QCR8:PHYFC1) 4 |
| 2. Is it hard for me to run | ☐ (QCR8:PHYFC2) 0 | ☐ (QCR8:PHYFC2) 1 | ☐ (QCR8:PHYFC2) 2 | ☐ (QCR8:PHYFC2) 3 | ☐ (QCR8:PHYFC2) 4 |
| 3. Is it hard for me to do sports activity or exercise | ☐ (QCR8:PHYFC3) 0 | ☐ (QCR8:PHYFC3) 1 | ☐ (QCR8:PHYFC3) 2 | ☐ (QCR8:PHYFC3) 3 | ☐ (QCR8:PHYFC3) 4 |
| 4. It is hard for me to lift something heavy | ☐ (QCR8:PHYFC4) 0 | ☐ (QCR8:PHYFC4) 1 | ☐ (QCR8:PHYFC4) 2 | ☐ (QCR8:PHYFC4) 3 | ☐ (QCR8:PHYFC4) 4 |
| 5. It is hard for me to take a bath or shower by myself | ☐ (QCR8:PHYFC5) 0 | ☐ (QCR8:PHYFC5) 1 | ☐ (QCR8:PHYFC5) 2 | ☐ (QCR8:PHYFC5) 3 | ☐ (QCR8:PHYFC5) 4 |
| 6. It is hard for me to do chores around the house | ☐ (QCR8:PHYFC6) 0 | ☐ (QCR8:PHYFC6) 1 | ☐ (QCR8:PHYFC6) 2 | ☐ (QCR8:PHYFC6) 3 | ☐ (QCR8:PHYFC6) 4 |
| 7. I hurt or ache | ☐ (QCR8:PHYFC7) 0 | ☐ (QCR8:PHYFC7) 1 | ☐ (QCR8:PHYFC7) 2 | ☐ (QCR8:PHYFC7) 3 | ☐ (QCR8:PHYFC7) 4 |
| 8. I have low energy | ☐ (QCR8:PHYFC8) 0 | ☐ (QCR8:PHYFC8) 1 | ☐ (QCR8:PHYFC8) 2 | ☐ (QCR8:PHYFC8) 3 | ☐ (QCR8:PHYFC8) 4 |

| **About My Feelings** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I feel afraid or scared | ☐ (QCR8:EMOFC1) 0 | ☐ (QCR8:EMOFC1) 1 | ☐ (QCR8:EMOFC1) 2 | ☐ (QCR8:EMOFC1) 3 | ☐ (QCR8:EMOFC1) 4 |
| 2. I feel sad or blue | ☐ (QCR8:EMOFC2) 0 | ☐ (QCR8:EMOFC2) 1 | ☐ (QCR8:EMOFC2) 2 | ☐ (QCR8:EMOFC2) 3 | ☐ (QCR8:EMOFC2) 4 |
| 3. I feel angry | ☐ (QCR8:EMOFC3) | ☐ (QCR8:EMOFC3) | ☐ (QCR8:EMOFC3) | ☐ (QCR8:EMOFC3) | ☐ (QCR8:EMOFC3) |

| | | | | | |
|---|---|---|---|---|---|
| | 0 | 1 | 2 | 3 | 4 |
| 4. I have trouble sleeping | ☐ (QCR8:EMOFC4) 0 | ☐ (QCR8:EMOFC4) 1 | ☐ (QCR8:EMOFC4) 2 | ☐ (QCR8:EMOFC4) 3 | ☐ (QCR8:EMOFC4) 4 |
| 5. I worry about what will happen to me | ☐ (QCR8:EMOFC5) 0 | ☐ (QCR8:EMOFC5) 1 | ☐ (QCR8:EMOFC5) 2 | ☐ (QCR8:EMOFC5) 3 | ☐ (QCR8:EMOFC5) 4 |

| **How I Get Along with Others** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I have trouble getting along with other kids | ☐ (QCR8:SOCFC1) 0 | ☐ (QCR8:SOCFC1) 1 | ☐ (QCR8:SOCFC1) 2 | ☐ (QCR8:SOCFC1) 3 | ☐ (QCR8:SOCFC1) 4 |
| 2. Other kids do not want to be my friend | ☐ (QCR8:SOCFC2) 0 | ☐ (QCR8:SOCFC2) 1 | ☐ (QCR8:SOCFC2) 2 | ☐ (QCR8:SOCFC2) 3 | ☐ (QCR8:SOCFC2) 4 |
| 3. Other kids tease me | ☐ (QCR8:SOCFC3) 0 | ☐ (QCR8:SOCFC3) 1 | ☐ (QCR8:SOCFC3) 2 | ☐ (QCR8:SOCFC3) 3 | ☐ (QCR8:SOCFC3) 4 |
| 4. I cannot do things that other kids my age can do | ☐ (QCR8:SOCFC4) 0 | ☐ (QCR8:SOCFC4) 1 | ☐ (QCR8:SOCFC4) 2 | ☐ (QCR8:SOCFC4) 3 | ☐ (QCR8:SOCFC4) 4 |
| 5. It is hard for me to keep up when I play with other kids | ☐ (QCR8:SOCFC5) 0 | ☐ (QCR8:SOCFC5) 1 | ☐ (QCR8:SOCFC5) 2 | ☐ (QCR8:SOCFC5) 3 | ☐ (QCR8:SOCFC5) 4 |

| **About School** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard to pay attention in class | ☐ (QCR8:SCHFC1) 0 | ☐ (QCR8:SCHFC1) 1 | ☐ (QCR8:SCHFC1) 2 | ☐ (QCR8:SCHFC1) 3 | ☐ (QCR8:SCHFC1) 4 |
| 2. I forget things | ☐ (QCR8:SCHFC2) 0 | ☐ (QCR8:SCHFC2) 1 | ☐ (QCR8:SCHFC2) 2 | ☐ (QCR8:SCHFC2) 3 | ☐ (QCR8:SCHFC2) 4 |
| 3. I have trouble keeping up with my schoolwork | ☐ (QCR8:SCHFC3) 0 | ☐ (QCR8:SCHFC3) 1 | ☐ (QCR8:SCHFC3) 2 | ☐ (QCR8:SCHFC3) 3 | ☐ (QCR8:SCHFC3) 4 |
| 4. I miss school because of not feeling well | ☐ (QCR8:SCHFC4) 0 | ☐ (QCR8:SCHFC4) 1 | ☐ (QCR8:SCHFC4) 2 | ☐ (QCR8:SCHFC4) 3 | ☐ (QCR8:SCHFC4) 4 |
| 5. I miss school to go to the doctor or hospital | ☐ (QCR8:SCHFC5) 0 | ☐ (QCR8:SCHFC5) 1 | ☐ (QCR8:SCHFC5) 2 | ☐ (QCR8:SCHFC5) 3 | ☐ (QCR8:SCHFC5) 4 |


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| Comprehensive Sickle Cell Centers | **Pediatric Quality of Life Inventory Parent Report for Child (8-12)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: QPC8:FORMDA / QPC8:FORMMO / QPC8:FORMYR (DD / MMM / YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has your child had with...***

| **Physical Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Walking more than one block | ☐ (QPC8:PHYFP1) 0 | ☐ (QPC8:PHYFP1) 1 | ☐ (QPC8:PHYFP1) 2 | ☐ (QPC8:PHYFP1) 3 | ☐ (QPC8:PHYFP1) 4 |
| 2. Running | ☐ (QPC8:PHYFP2) 0 | ☐ (QPC8:PHYFP2) 1 | ☐ (QPC8:PHYFP2) 2 | ☐ (QPC8:PHYFP2) 3 | ☐ (QPC8:PHYFP2) 4 |
| 3. Participating in sports activity or exercise | ☐ (QPC8:PHYFP3) 0 | ☐ (QPC8:PHYFP3) 1 | ☐ (QPC8:PHYFP3) 2 | ☐ (QPC8:PHYFP3) 3 | ☐ (QPC8:PHYFP3) 4 |
| 4. Lifting something heavy | ☐ (QPC8:PHYFP4) 0 | ☐ (QPC8:PHYFP4) 1 | ☐ (QPC8:PHYFP4) 2 | ☐ (QPC8:PHYFP4) 3 | ☐ (QPC8:PHYFP4) 4 |
| 5. Taking a bath or shower by him or herself | ☐ (QPC8:PHYFP5) 0 | ☐ (QPC8:PHYFP5) 1 | ☐ (QPC8:PHYFP5) 2 | ☐ (QPC8:PHYFP5) 3 | ☐ (QPC8:PHYFP5) 4 |
| 6. Doing chores, like picking up his or her toys | ☐ (QPC8:PHYFP6) 0 | ☐ (QPC8:PHYFP6) 1 | ☐ (QPC8:PHYFP6) 2 | ☐ (QPC8:PHYFP6) 3 | ☐ (QPC8:PHYFP6) 4 |
| 7. Having hurts or aches | ☐ (QPC8:PHYFP7) 0 | ☐ (QPC8:PHYFP7) 1 | ☐ (QPC8:PHYFP7) 2 | ☐ (QPC8:PHYFP7) 3 | ☐ (QPC8:PHYFP7) 4 |
| 8. Low energy level | ☐ (QPC8:PHYFP8) 0 | ☐ (QPC8:PHYFP8) 1 | ☐ (QPC8:PHYFP8) 2 | ☐ (QPC8:PHYFP8) 3 | ☐ (QPC8:PHYFP8) 4 |

| **Emotional Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling afraid or scared | ☐ (QPC8:EMOFP1) 0 | ☐ (QPC8:EMOFP1) 1 | ☐ (QPC8:EMOFP1) 2 | ☐ (QPC8:EMOFP1) 3 | ☐ (QPC8:EMOFP1) 4 |
| 2. Feeling sad or blue | ☐ (QPC8:EMOFP2) 0 | ☐ (QPC8:EMOFP2) 1 | ☐ (QPC8:EMOFP2) 2 | ☐ (QPC8:EMOFP2) 3 | ☐ (QPC8:EMOFP2) 4 |
| 3. Feeling angry | ☐ (QPC8:EMOFP3) 0 | ☐ (QPC8:EMOFP3) 1 | ☐ (QPC8:EMOFP3) 2 | ☐ (QPC8:EMOFP3) 3 | ☐ (QPC8:EMOFP3) 4 |
| 4. Trouble sleeping | ☐ (QPC8:EMOFP4) 0 | ☐ (QPC8:EMOFP4) 1 | ☐ (QPC8:EMOFP4) 2 | ☐ (QPC8:EMOFP4) 3 | ☐ (QPC8:EMOFP4) 4 |
| 5. Worrying about what will happen to him or her | ☐ (QPC8:EMOFP5) 0 | ☐ (QPC8:EMOFP5) 1 | ☐ (QPC8:EMOFP5) 2 | ☐ (QPC8:EMOFP5) 3 | ☐ (QPC8:EMOFP5) 4 |

| **Social Functioning *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Getting along with other children | ☐ (QPC8:SOCFP1) 0 | ☐ (QPC8:SOCFP1) 1 | ☐ (QPC8:SOCFP1) 2 | ☐ (QPC8:SOCFP1) 3 | ☐ (QPC8:SOCFP1) 4 |
| 2. Other kids not wanting to be his or her friend | ☐ (QPC8:SOCFP2) 0 | ☐ (QPC8:SOCFP2) 1 | ☐ (QPC8:SOCFP2) 2 | ☐ (QPC8:SOCFP2) 3 | ☐ (QPC8:SOCFP2) 4 |
| 3. Getting teased by other children | ☐ (QPC8:SOCFP3) 0 | ☐ (QPC8:SOCFP3) 1 | ☐ (QPC8:SOCFP3) 2 | ☐ (QPC8:SOCFP3) 3 | ☐ (QPC8:SOCFP3) 4 |
| 4. Not able to do things that other children his or her age can do | ☐ (QPC8:SOCFP4) 0 | ☐ (QPC8:SOCFP4) 1 | ☐ (QPC8:SOCFP4) 2 | ☐ (QPC8:SOCFP4) 3 | ☐ (QPC8:SOCFP4) 4 |
| 5. Keeping up when playing with other children | ☐ (QPC8:SOCFP5) 0 | ☐ (QPC8:SOCFP5) 1 | ☐ (QPC8:SOCFP5) 2 | ☐ (QPC8:SOCFP5) 3 | ☐ (QPC8:SOCFP5) 4 |

| **School Functioning *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Paying attention in class | ☐ (QPC8:SCHFP1) 0 | ☐ (QPC8:SCHFP1) 1 | ☐ (QPC8:SCHFP1) 2 | ☐ (QPC8:SCHFP1) 3 | ☐ (QPC8:SCHFP1) 4 |
| 2. Forgetting things | ☐ (QPC8:SCHFP2) 0 | ☐ (QPC8:SCHFP2) 1 | ☐ (QPC8:SCHFP2) 2 | ☐ (QPC8:SCHFP2) 3 | ☐ (QPC8:SCHFP2) 4 |
| 3. Keeping up with schoolwork | ☐ (QPC8:SCHFP3) 0 | ☐ (QPC8:SCHFP3) 1 | ☐ (QPC8:SCHFP3) 2 | ☐ (QPC8:SCHFP3) 3 | ☐ (QPC8:SCHFP3) 4 |
| 4. Missing school because of not feeling well | ☐ (QPC8:SCHFP4) 0 | ☐ (QPC8:SCHFP4) 1 | ☐ (QPC8:SCHFP4) 2 | ☐ (QPC8:SCHFP4) 3 | ☐ (QPC8:SCHFP4) 4 |
| 5. Missing school to go to the doctor or hospital | ☐ (QPC8:SCHFP5) 0 | ☐ (QPC8:SCHFP5) 1 | ☐ (QPC8:SCHFP5) 2 | ☐ (QPC8:SCHFP5) 3 | ☐ (QPC8:SCHFP5) 4 |

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| Comprehensive Sickle Cell Centers | **Multidimensional Fatigue Scale Child Report (8-12)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: FCC8:FORMDA (DD) / FCC8:FORMMO (MMM) / FCC8:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for you...***

| **General Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I feel tired | ☐ (FCC8:GEN1) 0 | ☐ (FCC8:GEN1) 1 | ☐ (FCC8:GEN1) 2 | ☐ (FCC8:GEN1) 3 | ☐ (FCC8:GEN1) 4 |
| 2. I feel physically weak (not strong) | ☐ (FCC8:GEN2) 0 | ☐ (FCC8:GEN2) 1 | ☐ (FCC8:GEN2) 2 | ☐ (FCC8:GEN2) 3 | ☐ (FCC8:GEN2) 4 |
| 3. I feel too tired to do things that I like to do | ☐ (FCC8:GEN3) 0 | ☐ (FCC8:GEN3) 1 | ☐ (FCC8:GEN3) 2 | ☐ (FCC8:GEN3) 3 | ☐ (FCC8:GEN3) 4 |
| 4. I feel too tired to spend time with my friends | ☐ (FCC8:GEN4) 0 | ☐ (FCC8:GEN4) 1 | ☐ (FCC8:GEN4) 2 | ☐ (FCC8:GEN4) 3 | ☐ (FCC8:GEN4) 4 |
| 5. I have trouble finishing things | ☐ (FCC8:GEN5) 0 | ☐ (FCC8:GEN5) 1 | ☐ (FCC8:GEN5) 2 | ☐ (FCC8:GEN5) 3 | ☐ (FCC8:GEN5) 4 |
| 6. I have trouble starting things | ☐ (FCC8:GEN6) 0 | ☐ (FCC8:GEN6) 1 | ☐ (FCC8:GEN6) 2 | ☐ (FCC8:GEN6) 3 | ☐ (FCC8:GEN6) 4 |

| **Sleep/Rest Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I sleep a lot | ☐ (FCC8:SLEEP1) 0 | ☐ (FCC8:SLEEP1) 1 | ☐ (FCC8:SLEEP1) 2 | ☐ (FCC8:SLEEP1) 3 | ☐ (FCC8:SLEEP1) 4 |
| 2. It is hard for me to sleep through the night | ☐ (FCC8:SLEEP2) 0 | ☐ (FCC8:SLEEP2) 1 | ☐ (FCC8:SLEEP2) 2 | ☐ (FCC8:SLEEP2) 3 | ☐ (FCC8:SLEEP2) 4 |
| 3. I feel tired when I wake up in the morning | ☐ (FCC8:SLEEP3) 0 | ☐ (FCC8:SLEEP3) 1 | ☐ (FCC8:SLEEP3) 2 | ☐ (FCC8:SLEEP3) 3 | ☐ (FCC8:SLEEP3) 4 |
| 4. I rest a lot | ☐ (FCC8:SLEEP4) 0 | ☐ (FCC8:SLEEP4) 1 | ☐ (FCC8:SLEEP4) 2 | ☐ (FCC8:SLEEP4) 3 | ☐ (FCC8:SLEEP4) 4 |
| 5. I take a lot of naps | ☐ (FCC8:SLEEP5) 0 | ☐ (FCC8:SLEEP5) 1 | ☐ (FCC8:SLEEP5) 2 | ☐ (FCC8:SLEEP5) 3 | ☐ (FCC8:SLEEP5) 4 |
| 6. I spend a lot of time in bed | ☐ (FCC8:SLEEP6) 0 | ☐ (FCC8:SLEEP6) 1 | ☐ (FCC8:SLEEP6) 2 | ☐ (FCC8:SLEEP6) 3 | ☐ (FCC8:SLEEP6) 4 |

| **Cognitive Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard for me to keep my attention on things | ☐ (FCC8:COGNI1) 0 | ☐ (FCC8:COGNI1) 1 | ☐ (FCC8:COGNI1) 2 | ☐ (FCC8:COGNI1) 3 | ☐ (FCC8:COGNI1) 4 |
| 2. It is hard for me to remember | ☐ (FCC8:COGNI2) 0 | ☐ (FCC8:COGNI2) 1 | ☐ (FCC8:COGNI2) 2 | ☐ (FCC8:COGNI2) 3 | ☐ (FCC8:COGNI2) 4 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | what people tell me | | | | | |
| 3. | It is hard for me to remember what I just heard | ☐ (FCC8:COGNI3) 0 | ☐ (FCC8:COGNI3) 1 | ☐ (FCC8:COGNI3) 2 | ☐ (FCC8:COGNI3) 3 | ☐ (FCC8:COGNI3) 4 |
| 4. | It is hard for me to think quickly | ☐ (FCC8:COGNI4) 0 | ☐ (FCC8:COGNI4) 1 | ☐ (FCC8:COGNI4) 2 | ☐ (FCC8:COGNI4) 3 | ☐ (FCC8:COGNI4) 4 |
| 5. | I have trouble remembering what I was just thinking | ☐ (FCC8:COGNI5) 0 | ☐ (FCC8:COGNI5) 1 | ☐ (FCC8:COGNI5) 2 | ☐ (FCC8:COGNI5) 3 | ☐ (FCC8:COGNI5) 4 |
| 6. | I have trouble remembering more than one thing at a time | ☐ (FCC8:COGNI6) 0 | ☐ (FCC8:COGNI6) 1 | ☐ (FCC8:COGNI6) 2 | ☐ (FCC8:COGNI6) 3 | ☐ (FCC8:COGNI6) 4 |

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| Comprehensive Sickle Cell Centers | **Multidimensional Fatigue Scale Parent Report for Child (8-12)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: FPC8:FORMDA (DD) / FPC8:FORMMO (MMM) / FPC8:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for your child...***

| **General Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling tired | ☐ (FPC8:GEN1) 0 | ☐ (FPC8:GEN1) 1 | ☐ (FPC8:GEN1) 2 | ☐ (FPC8:GEN1) 3 | ☐ (FPC8:GEN1) 4 |
| 2. Feeling physically weak (not strong) | ☐ (FPC8:GEN2) 0 | ☐ (FPC8:GEN2) 1 | ☐ (FPC8:GEN2) 2 | ☐ (FPC8:GEN2) 3 | ☐ (FPC8:GEN2) 4 |
| 3. Feeling too tired to do things that he/she likes to do | ☐ (FPC8:GEN3) 0 | ☐ (FPC8:GEN3) 1 | ☐ (FPC8:GEN3) 2 | ☐ (FPC8:GEN3) 3 | ☐ (FPC8:GEN3) 4 |
| 4. Feeling too tired to spend time with his/her friends | ☐ (FPC8:GEN4) 0 | ☐ (FPC8:GEN4) 1 | ☐ (FPC8:GEN4) 2 | ☐ (FPC8:GEN4) 3 | ☐ (FPC8:GEN4) 4 |
| 5. Trouble finishing things | ☐ (FPC8:GEN5) 0 | ☐ (FPC8:GEN5) 1 | ☐ (FPC8:GEN5) 2 | ☐ (FPC8:GEN5) 3 | ☐ (FPC8:GEN5) 4 |
| 6. Trouble starting things | ☐ (FPC8:GEN6) 0 | ☐ (FPC8:GEN6) 1 | ☐ (FPC8:GEN6) 2 | ☐ (FPC8:GEN6) 3 | ☐ (FPC8:GEN6) 4 |

| **Sleep/Rest Fatigue** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Sleeping a lot | ☐ (FPC8:SLEEP1) 0 | ☐ (FPC8:SLEEP1) 1 | ☐ (FPC8:SLEEP1) 2 | ☐ (FPC8:SLEEP1) 3 | ☐ (FPC8:SLEEP1) 4 |
| 2. Difficulty sleeping through the night | ☐ (FPC8:SLEEP2) 0 | ☐ (FPC8:SLEEP2) 1 | ☐ (FPC8:SLEEP2) 2 | ☐ (FPC8:SLEEP2) 3 | ☐ (FPC8:SLEEP2) 4 |
| 3. Feeling tired when he/she wakes up in the morning | ☐ (FPC8:SLEEP3) 0 | ☐ (FPC8:SLEEP3) 1 | ☐ (FPC8:SLEEP3) 2 | ☐ (FPC8:SLEEP3) 3 | ☐ (FPC8:SLEEP3) 4 |
| 4. Resting a lot | ☐ (FPC8:SLEEP4) 0 | ☐ (FPC8:SLEEP4) 1 | ☐ (FPC8:SLEEP4) 2 | ☐ (FPC8:SLEEP4) 3 | ☐ (FPC8:SLEEP4) 4 |
| 5. Taking a lot of naps | ☐ (FPC8:SLEEP5) 0 | ☐ (FPC8:SLEEP5) 1 | ☐ (FPC8:SLEEP5) 2 | ☐ (FPC8:SLEEP5) 3 | ☐ (FPC8:SLEEP5) 4 |
| 6. Spending a lot of time in bed | ☐ (FPC8:SLEEP6) 0 | ☐ (FPC8:SLEEP6) 1 | ☐ (FPC8:SLEEP6) 2 | ☐ (FPC8:SLEEP6) 3 | ☐ (FPC8:SLEEP6) 4 |

| **Cognitive Fatigue** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty keeping his/her attention on | ☐ (FPC8:COGNI1) 0 | ☐ (FPC8:COGNI1) 1 | ☐ (FPC8:COGNI1) 2 | ☐ (FPC8:COGNI1) 3 | ☐ (FPC8:COGNI1) 4 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | things | | | | | |
| 2. | Difficulty remembering what people tell him/her | ☐ (FPC8:COGNI2) 0 | ☐ (FPC8:COGNI2) 1 | ☐ (FPC8:COGNI2) 2 | ☐ (FPC8:COGNI2) 3 | ☐ (FPC8:COGNI2) 4 |
| 3. | Difficulty remembering what he/she just heard | ☐ (FPC8:COGNI3) 0 | ☐ (FPC8:COGNI3) 1 | ☐ (FPC8:COGNI3) 2 | ☐ (FPC8:COGNI3) 3 | ☐ (FPC8:COGNI3) 4 |
| 4. | Difficulty thinking quickly | ☐ (FPC8:COGNI4) 0 | ☐ (FPC8:COGNI4) 1 | ☐ (FPC8:COGNI4) 2 | ☐ (FPC8:COGNI4) 3 | ☐ (FPC8:COGNI4) 4 |
| 5. | Trouble remembering what he/she was just thinking | ☐ (FPC8:COGNI5) 0 | ☐ (FPC8:COGNI5) 1 | ☐ (FPC8:COGNI5) 2 | ☐ (FPC8:COGNI5) 3 | ☐ (FPC8:COGNI5) 4 |
| 6. | Trouble remembering more than one thing at a time | ☐ (FPC8:COGNI6) 0 | ☐ (FPC8:COGNI6) 1 | ☐ (FPC8:COGNI6) 2 | ☐ (FPC8:COGNI6) 3 | ☐ (FPC8:COGNI6) 4 |

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| Comprehensive Sickle Cell Centers | **Pediatric Pain Questionnaire Child Form (8-12)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PQC8:FORMDA (DD) / PQC8:FORMMO (MMM) / PQC8:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

What words would you use to describe your pain or hurt?

PQC8:PAINWRD

Using a metric ruler, measure the distance of the subject's mark from the left-hand anchor on the line of the paper form completed by the patient. In the box below, enter the number in millimeters. Measure to the nearest whole millimeter. A mark drawn exactly on the left-hand anchor (No pain) should be entered as 0 and a mark drawn exactly on the right-hand anchor should be entered as 100 (Severe Pain).

Now: PQC8:PAINNOW

This Week: PQC8:PAINWK

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| Comprehensive Sickle Cell Centers | **Pediatric Pain Questionnaire Parent of Child Form (8-12)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PQP8:FORMDA (DD) / PQP8:FORMMO (MMM) / PQP8:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

What words would you use to describe your child's pain or hurt?

PQP8:PAINWRD

Using a metric ruler, measure the distance of the parent's mark from the left-hand anchor on the line of the paper form completed by the parent. In the box below, enter the number in millimeters. Measure to the nearest whole millimeter. A mark drawn exactly on the left-hand anchor (No pain) should be entered as 0 and a mark drawn exactly on the right-hand anchor should be entered as 100 (Severe Pain).

Now: PQP8:PAINNOW

Past Week: PQP8:PAINWK

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| Comprehensive Sickle Cell Centers | **Pediatric Quality of Life Inventory Teen Report (13-18)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: QC13:FORMDA / QC13:FORMMO / QC13:FORMYR (DD / MMM / YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for you...***

| **About My Health and Activities *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard for me to walk more than one block | ☐ (QC13:PHYFC1) 0 | ☐ (QC13:PHYFC1) 1 | ☐ (QC13:PHYFC1) 2 | ☐ (QC13:PHYFC1) 3 | ☐ (QC13:PHYFC1) 4 |
| 2. It is hard for me to run | ☐ (QC13:PHYFC2) 0 | ☐ (QC13:PHYFC2) 1 | ☐ (QC13:PHYFC2) 2 | ☐ (QC13:PHYFC2) 3 | ☐ (QC13:PHYFC2) 4 |
| 3. It is hard for me to do sports activity or exercise | ☐ (QC13:PHYFC3) 0 | ☐ (QC13:PHYFC3) 1 | ☐ (QC13:PHYFC3) 2 | ☐ (QC13:PHYFC3) 3 | ☐ (QC13:PHYFC3) 4 |
| 4. It is hard for me to lift something heavy | ☐ (QC13:PHYFC4) 0 | ☐ (QC13:PHYFC4) 1 | ☐ (QC13:PHYFC4) 2 | ☐ (QC13:PHYFC4) 3 | ☐ (QC13:PHYFC4) 4 |
| 5. It is hard for me to take a bath or shower by myself | ☐ (QC13:PHYFC5) 0 | ☐ (QC13:PHYFC5) 1 | ☐ (QC13:PHYFC5) 2 | ☐ (QC13:PHYFC5) 3 | ☐ (QC13:PHYFC5) 4 |
| 6. It is hard for me to do chores around the house | ☐ (QC13:PHYFC6) 0 | ☐ (QC13:PHYFC6) 1 | ☐ (QC13:PHYFC6) 2 | ☐ (QC13:PHYFC6) 3 | ☐ (QC13:PHYFC6) 4 |
| 7. I hurt or ache | ☐ (QC13:PHYFC7) 0 | ☐ (QC13:PHYFC7) 1 | ☐ (QC13:PHYFC7) 2 | ☐ (QC13:PHYFC7) 3 | ☐ (QC13:PHYFC7) 4 |
| 8. I have low energy | ☐ (QC13:PHYFC8) 0 | ☐ (QC13:PHYFC8) 1 | ☐ (QC13:PHYFC8) 2 | ☐ (QC13:PHYFC8) 3 | ☐ (QC13:PHYFC8) 4 |

| **About My Feelings *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I feel afraid or scared | ☐ (QC13:EMOFC1) 0 | ☐ (QC13:EMOFC1) 1 | ☐ (QC13:EMOFC1) 2 | ☐ (QC13:EMOFC1) 3 | ☐ (QC13:EMOFC1) 4 |
| 2. I feel sad or blue | ☐ (QC13:EMOFC2) 0 | ☐ (QC13:EMOFC2) 1 | ☐ (QC13:EMOFC2) 2 | ☐ (QC13:EMOFC2) 3 | ☐ (QC13:EMOFC2) 4 |
| 3. I feel angry | ☐ (QC13:EMOFC3) 0 | ☐ (QC13:EMOFC3) 1 | ☐ (QC13:EMOFC3) 2 | ☐ (QC13:EMOFC3) 3 | ☐ (QC13:EMOFC3) 4 |
| 4. I have | ☐ (QC13:EMOFC4) | ☐ (QC13:EMOFC4) | ☐ (QC13:EMOFC4) | ☐ (QC13:EMOFC4) | ☐ (QC13:EMOFC4) |

| | | | | | |
|---|---|---|---|---|---|
| trouble sleeping | 0 | 1 | 2 | 3 | 4 |
| 5. I worry about what will happen to me | ☐ (QC13:EMOFC5) 0 | ☐ (QC13:EMOFC5) 1 | ☐ (QC13:EMOFC5) 2 | ☐ (QC13:EMOFC5) 3 | ☐ (QC13:EMOFC5) 4 |

| **How I Get Along With Others** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I have trouble getting along with other teens | ☐ (QC13:SOCFC1) 0 | ☐ (QC13:SOCFC1) 1 | ☐ (QC13:SOCFC1) 2 | ☐ (QC13:SOCFC1) 3 | ☐ (QC13:SOCFC1) 4 |
| 2. Other teens do not want to be my friend | ☐ (QC13:SOCFC2) 0 | ☐ (QC13:SOCFC2) 1 | ☐ (QC13:SOCFC2) 2 | ☐ (QC13:SOCFC2) 3 | ☐ (QC13:SOCFC2) 4 |
| 3. Other teens tease me | ☐ (QC13:SOCFC3) 0 | ☐ (QC13:SOCFC3) 1 | ☐ (QC13:SOCFC3) 2 | ☐ (QC13:SOCFC3) 3 | ☐ (QC13:SOCFC3) 4 |
| 4. I cannot do things that other teens my age can do | ☐ (QC13:SOCFC4) 0 | ☐ (QC13:SOCFC4) 1 | ☐ (QC13:SOCFC4) 2 | ☐ (QC13:SOCFC4) 3 | ☐ (QC13:SOCFC4) 4 |
| 5. It is hard for me to keep up with my peers | ☐ (QC13:SOCFC5) 0 | ☐ (QC13:SOCFC5) 1 | ☐ (QC13:SOCFC5) 2 | ☐ (QC13:SOCFC5) 3 | ☐ (QC13:SOCFC5) 4 |

| **About School** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard to pay attention in class | ☐ (QC13:SCHFC1) 0 | ☐ (QC13:SCHFC1) 1 | ☐ (QC13:SCHFC1) 2 | ☐ (QC13:SCHFC1) 3 | ☐ (QC13:SCHFC1) 4 |
| 2. I forget things | ☐ (QC13:SCHFC2) 0 | ☐ (QC13:SCHFC2) 1 | ☐ (QC13:SCHFC2) 2 | ☐ (QC13:SCHFC2) 3 | ☐ (QC13:SCHFC2) 4 |
| 3. I have trouble keeping up with my schoolwork | ☐ (QC13:SCHFC3) 0 | ☐ (QC13:SCHFC3) 1 | ☐ (QC13:SCHFC3) 2 | ☐ (QC13:SCHFC3) 3 | ☐ (QC13:SCHFC3) 4 |
| 4. I miss school because of not feeling well | ☐ (QC13:SCHFC4) 0 | ☐ (QC13:SCHFC4) 1 | ☐ (QC13:SCHFC4) 2 | ☐ (QC13:SCHFC4) 3 | ☐ (QC13:SCHFC4) 4 |
| 5. I miss school to go to the doctor or hospital | ☐ (QC13:SCHFC5) 0 | ☐ (QC13:SCHFC5) 1 | ☐ (QC13:SCHFC5) 2 | ☐ (QC13:SCHFC5) 3 | ☐ (QC13:SCHFC5) 4 |

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| Comprehensive Sickle Cell Centers | **Pediatric Quality of Life Inventory Parent Report for Teens (13-18)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: QP13:FORMDA (DD) / QP13:FORMMO (MMM) / QP13:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has your teen had with...***

| **Physical Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Walking more than one block | ☐ (QP13:PHYFP1) 0 | ☐ (QP13:PHYFP1) 1 | ☐ (QP13:PHYFP1) 2 | ☐ (QP13:PHYFP1) 3 | ☐ (QP13:PHYFP1) 4 |
| 2. Running | ☐ (QP13:PHYFP2) 0 | ☐ (QP13:PHYFP2) 1 | ☐ (QP13:PHYFP2) 2 | ☐ (QP13:PHYFP2) 3 | ☐ (QP13:PHYFP2) 4 |
| 3. Participating in sports activity or exercise | ☐ (QP13:PHYFP3) 0 | ☐ (QP13:PHYFP3) 1 | ☐ (QP13:PHYFP3) 2 | ☐ (QP13:PHYFP3) 3 | ☐ (QP13:PHYFP3) 4 |
| 4. Lifting something heavy | ☐ (QP13:PHYFP4) 0 | ☐ (QP13:PHYFP4) 1 | ☐ (QP13:PHYFP4) 2 | ☐ (QP13:PHYFP4) 3 | ☐ (QP13:PHYFP4) 4 |
| 5. Taking a bath or shower by him or herself | ☐ (QP13:PHYFP5) 0 | ☐ (QP13:PHYFP5) 1 | ☐ (QP13:PHYFP5) 2 | ☐ (QP13:PHYFP5) 3 | ☐ (QP13:PHYFP5) 4 |
| 6. Doing chores around the house | ☐ (QP13:PHYFP6) 0 | ☐ (QP13:PHYFP6) 1 | ☐ (QP13:PHYFP6) 2 | ☐ (QP13:PHYFP6) 3 | ☐ (QP13:PHYFP6) 4 |
| 7. Having hurts or aches | ☐ (QP13:PHYFP7) 0 | ☐ (QP13:PHYFP7) 1 | ☐ (QP13:PHYFP7) 2 | ☐ (QP13:PHYFP7) 3 | ☐ (QP13:PHYFP7) 4 |
| 8. Low energy level | ☐ (QP13:PHYFP8) 0 | ☐ (QP13:PHYFP8) 1 | ☐ (QP13:PHYFP8) 2 | ☐ (QP13:PHYFP8) 3 | ☐ (QP13:PHYFP8) 4 |

| **Emotional Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling afraid or scared | ☐ (QP13:EMOFP1) 0 | ☐ (QP13:EMOFP1) 1 | ☐ (QP13:EMOFP1) 2 | ☐ (QP13:EMOFP1) 3 | ☐ (QP13:EMOFP1) 4 |
| 2. Feeling sad or blue | ☐ (QP13:EMOFP2) 0 | ☐ (QP13:EMOFP2) 1 | ☐ (QP13:EMOFP2) 2 | ☐ (QP13:EMOFP2) 3 | ☐ (QP13:EMOFP2) 4 |
| 3. Feeling angry | ☐ (QP13:EMOFP3) 0 | ☐ (QP13:EMOFP3) 1 | ☐ (QP13:EMOFP3) 2 | ☐ (QP13:EMOFP3) 3 | ☐ (QP13:EMOFP3) 4 |
| 4. Trouble sleeping | ☐ (QP13:EMOFP4) 0 | ☐ (QP13:EMOFP4) 1 | ☐ (QP13:EMOFP4) 2 | ☐ (QP13:EMOFP4) 3 | ☐ (QP13:EMOFP4) 4 |
| 5. Worrying about what will happen to him or her | ☐ (QP13:EMOFP5) 0 | ☐ (QP13:EMOFP5) 1 | ☐ (QP13:EMOFP5) 2 | ☐ (QP13:EMOFP5) 3 | ☐ (QP13:EMOFP5) 4 |

| **Social** | Never | Almost | Some- | Often | Almost |
|---|---|---|---|---|---|

| **Functioning** ***(problems with...)*** | Never | | times | | Always |
|---|---|---|---|---|---|
| 1. Getting along with other teens | ☐ (QP13:SOCFP1) 0 | ☐ (QP13:SOCFP1) 1 | ☐ (QP13:SOCFP1) 2 | ☐ (QP13:SOCFP1) 3 | ☐ (QP13:SOCFP1) 4 |
| 2. Other teens not wanting to be his or her friend | ☐ (QP13:SOCFP2) 0 | ☐ (QP13:SOCFP2) 1 | ☐ (QP13:SOCFP2) 2 | ☐ (QP13:SOCFP2) 3 | ☐ (QP13:SOCFP2) 4 |
| 3. Getting teased by other teens | ☐ (QP13:SOCFP3) 0 | ☐ (QP13:SOCFP3) 1 | ☐ (QP13:SOCFP3) 2 | ☐ (QP13:SOCFP3) 3 | ☐ (QP13:SOCFP3) 4 |
| 4. Not able to do things that other teens his or her age can do | ☐ (QP13:SOCFP4) 0 | ☐ (QP13:SOCFP4) 1 | ☐ (QP13:SOCFP4) 2 | ☐ (QP13:SOCFP4) 3 | ☐ (QP13:SOCFP4) 4 |
| 5. Keeping up with other teens | ☐ (QP13:SOCFP5) 0 | ☐ (QP13:SOCFP5) 1 | ☐ (QP13:SOCFP5) 2 | ☐ (QP13:SOCFP5) 3 | ☐ (QP13:SOCFP5) 4 |

| **School Functioning** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Paying attention in class | ☐ (QP13:SCHFP1) 0 | ☐ (QP13:SCHFP1) 1 | ☐ (QP13:SCHFP1) 2 | ☐ (QP13:SCHFP1) 3 | ☐ (QP13:SCHFP1) 4 |
| 2. Forgetting things | ☐ (QP13:SCHFP2) 0 | ☐ (QP13:SCHFP2) 1 | ☐ (QP13:SCHFP2) 2 | ☐ (QP13:SCHFP2) 3 | ☐ (QP13:SCHFP2) 4 |
| 3. Keeping up with schoolwork | ☐ (QP13:SCHFP3) 0 | ☐ (QP13:SCHFP3) 1 | ☐ (QP13:SCHFP3) 2 | ☐ (QP13:SCHFP3) 3 | ☐ (QP13:SCHFP3) 4 |
| 4. Missing school because of not feeling well | ☐ (QP13:SCHFP4) 0 | ☐ (QP13:SCHFP4) 1 | ☐ (QP13:SCHFP4) 2 | ☐ (QP13:SCHFP4) 3 | ☐ (QP13:SCHFP4) 4 |
| 5. Missing school to go to the doctor or hospital | ☐ (QP13:SCHFP5) 0 | ☐ (QP13:SCHFP5) 1 | ☐ (QP13:SCHFP5) 2 | ☐ (QP13:SCHFP5) 3 | ☐ (QP13:SCHFP5) 4 |

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| Comprehensive Sickle Cell Centers | **Multidimensional Fatigue Scale Teen Report (13-18)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: FC13:FORMDA (DD) / FC13:FORMMO (MMM) / FC13:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for you...***

| **General Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I feel tired | ☐ (FC13:GEN1) 0 | ☐ (FC13:GEN1) 1 | ☐ (FC13:GEN1) 2 | ☐ (FC13:GEN1) 3 | ☐ (FC13:GEN1) 4 |
| 2. I feel physically weak (not strong) | ☐ (FC13:GEN2) 0 | ☐ (FC13:GEN2) 1 | ☐ (FC13:GEN2) 2 | ☐ (FC13:GEN2) 3 | ☐ (FC13:GEN2) 4 |
| 3. I feel too tired to do things that I like to do | ☐ (FC13:GEN3) 0 | ☐ (FC13:GEN3) 1 | ☐ (FC13:GEN3) 2 | ☐ (FC13:GEN3) 3 | ☐ (FC13:GEN3) 4 |
| 4. I feel too tired to spend time with my friends | ☐ (FC13:GEN4) 0 | ☐ (FC13:GEN4) 1 | ☐ (FC13:GEN4) 2 | ☐ (FC13:GEN4) 3 | ☐ (FC13:GEN4) 4 |
| 5. I have trouble finishing things | ☐ (FC13:GEN5) 0 | ☐ (FC13:GEN5) 1 | ☐ (FC13:GEN5) 2 | ☐ (FC13:GEN5) 3 | ☐ (FC13:GEN5) 4 |
| 6. I have trouble starting things | ☐ (FC13:GEN6) 0 | ☐ (FC13:GEN6) 1 | ☐ (FC13:GEN6) 2 | ☐ (FC13:GEN6) 3 | ☐ (FC13:GEN6) 4 |

| **Sleep/Rest Fatigue** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I sleep a lot | ☐ (FC13:SLEEP1) 0 | ☐ (FC13:SLEEP1) 1 | ☐ (FC13:SLEEP1) 2 | ☐ (FC13:SLEEP1) 3 | ☐ (FC13:SLEEP1) 4 |
| 2. It is hard for me to sleep through the night | ☐ (FC13:SLEEP2) 0 | ☐ (FC13:SLEEP2) 1 | ☐ (FC13:SLEEP2) 2 | ☐ (FC13:SLEEP2) 3 | ☐ (FC13:SLEEP2) 4 |
| 3. I feel tired when I wake up in the morning | ☐ (FC13:SLEEP3) 0 | ☐ (FC13:SLEEP3) 1 | ☐ (FC13:SLEEP3) 2 | ☐ (FC13:SLEEP3) 3 | ☐ (FC13:SLEEP3) 4 |
| 4. I rest a lot | ☐ (FC13:SLEEP4) 0 | ☐ (FC13:SLEEP4) 1 | ☐ (FC13:SLEEP4) 2 | ☐ (FC13:SLEEP4) 3 | ☐ (FC13:SLEEP4) 4 |
| 5. I take a lot of naps | ☐ (FC13:SLEEP5) 0 | ☐ (FC13:SLEEP5) 1 | ☐ (FC13:SLEEP5) 2 | ☐ (FC13:SLEEP5) 3 | ☐ (FC13:SLEEP5) 4 |
| 6. I spend a lot of time in bed | ☐ (FC13:SLEEP6) 0 | ☐ (FC13:SLEEP6) 1 | ☐ (FC13:SLEEP6) 2 | ☐ (FC13:SLEEP6) 3 | ☐ (FC13:SLEEP6) 4 |

| **Cognitive Fatigue** ***(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard for me to keep my attention on things | ☐ (FC13:COGNI1) 0 | ☐ (FC13:COGNI1) 1 | ☐ (FC13:COGNI1) 2 | ☐ (FC13:COGNI1) 3 | ☐ (FC13:COGNI1) 4 |
| 2. It is hard for me to remember | ☐ (FC13:COGNI2) 0 | ☐ (FC13:COGNI2) 1 | ☐ (FC13:COGNI2) 2 | ☐ (FC13:COGNI2) 3 | ☐ (FC13:COGNI2) 4 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | what people tell me | | | | | |
| 3. | It is hard for me to remember what I just heard | ☐ (FC13:COGNI3) 0 | ☐ (FC13:COGNI3) 1 | ☐ (FC13:COGNI3) 2 | ☐ (FC13:COGNI3) 3 | ☐ (FC13:COGNI3) 4 |
| 4. | It is hard for me to think quickly | ☐ (FC13:COGNI4) 0 | ☐ (FC13:COGNI4) 1 | ☐ (FC13:COGNI4) 2 | ☐ (FC13:COGNI4) 3 | ☐ (FC13:COGNI4) 4 |
| 5. | I have trouble remembering what I was just thinking | ☐ (FC13:COGNI5) 0 | ☐ (FC13:COGNI5) 1 | ☐ (FC13:COGNI5) 2 | ☐ (FC13:COGNI5) 3 | ☐ (FC13:COGNI5) 4 |
| 6. | I have trouble remembering more than one thing at a time | ☐ (FC13:COGNI6) 0 | ☐ (FC13:COGNI6) 1 | ☐ (FC13:COGNI6) 2 | ☐ (FC13:COGNI6) 3 | ☐ (FC13:COGNI6) 4 |

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| Comprehensive Sickle Cell Centers | **Multidimensional Fatigue Scale Parent Report for Teens (13-18)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: FP13:FORMDA (DD) / FP13:FORMMO (MMM) / FP13:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

***In the past ONE month, how much of a problem has this been for your child...***

| **General Fatigue *(problems with...)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling tired | ☐ (FP13:GEN1) 0 | ☐ (FP13:GEN1) 1 | ☐ (FP13:GEN1) 2 | ☐ (FP13:GEN1) 3 | ☐ (FP13:GEN1) 4 |
| 2. Feeling physically weak (not strong) | ☐ (FP13:GEN2) 0 | ☐ (FP13:GEN2) 1 | ☐ (FP13:GEN2) 2 | ☐ (FP13:GEN2) 3 | ☐ (FP13:GEN2) 4 |
| 3. Feeling too tired to do things that he/she likes to do | ☐ (FP13:GEN3) 0 | ☐ (FP13:GEN3) 1 | ☐ (FP13:GEN3) 2 | ☐ (FP13:GEN3) 3 | ☐ (FP13:GEN3) 4 |
| 4. Feeling too tired to spend time with his/her friends | ☐ (FP13:GEN4) 0 | ☐ (FP13:GEN4) 1 | ☐ (FP13:GEN4) 2 | ☐ (FP13:GEN4) 3 | ☐ (FP13:GEN4) 4 |
| 5. Trouble finishing things | ☐ (FP13:GEN5) 0 | ☐ (FP13:GEN5) 1 | ☐ (FP13:GEN5) 2 | ☐ (FP13:GEN5) 3 | ☐ (FP13:GEN5) 4 |
| 6. Trouble starting things | ☐ (FP13:GEN6) | ☐ (FP13:GEN6) | ☐ (FP13:GEN6) | ☐ (FP13:GEN6) | ☐ (FP13:GEN6) |

| | | 0 | 1 | 2 | 3 | 4 |
|---|---|---|---|---|---|---|
| **Sleep/Rest Fatigue** ***(problems with...)*** | | Never | Almost Never | Some-times | Often | Almost Always |
| 1. | Sleeping a lot | ☐ (FP13:SLEEP1) 0 | ☐ (FP13:SLEEP1) 1 | ☐ (FP13:SLEEP1) 2 | ☐ (FP13:SLEEP1) 3 | ☐ (FP13:SLEEP1) 4 |
| 2. | Difficulty sleeping through the night | ☐ (FP13:SLEEP2) 0 | ☐ (FP13:SLEEP2) 1 | ☐ (FP13:SLEEP2) 2 | ☐ (FP13:SLEEP2) 3 | ☐ (FP13:SLEEP2) 4 |
| 3. | Feeling tired when he/she wakes up in the morning | ☐ (FP13:SLEEP3) 0 | ☐ (FP13:SLEEP3) 1 | ☐ (FP13:SLEEP3) 2 | ☐ (FP13:SLEEP3) 3 | ☐ (FP13:SLEEP3) 4 |
| 4. | Resting a lot | ☐ (FP13:SLEEP4) 0 | ☐ (FP13:SLEEP4) 1 | ☐ (FP13:SLEEP4) 2 | ☐ (FP13:SLEEP4) 3 | ☐ (FP13:SLEEP4) 4 |
| 5. | Taking a lot of naps | ☐ (FP13:SLEEP5) 0 | ☐ (FP13:SLEEP5) 1 | ☐ (FP13:SLEEP5) 2 | ☐ (FP13:SLEEP5) 3 | ☐ (FP13:SLEEP5) 4 |
| 6. | Spending a lot of time in bed | ☐ (FP13:SLEEP6) 0 | ☐ (FP13:SLEEP6) 1 | ☐ (FP13:SLEEP6) 2 | ☐ (FP13:SLEEP6) 3 | ☐ (FP13:SLEEP6) 4 |
| **Cognitive Fatigue** ***(problems with...)*** | | Never | Almost Never | Some-times | Often | Almost Always |
| 1. | Difficulty keeping his/her attention on things | ☐ (FP13:COGNI1) 0 | ☐ (FP13:COGNI1) 1 | ☐ (FP13:COGNI1) 2 | ☐ (FP13:COGNI1) 3 | ☐ (FP13:COGNI1) 4 |
| 2. | Difficulty | ☐ (FP13:COGNI2) | ☐ (FP13:COGNI2) | ☐ (FP13:COGNI2) | ☐ (FP13:COGNI2) | ☐ (FP13:COGNI2) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | remembering what people tell him/her | 0 | 1 | 2 | 3 | 4 |
| 3. | Difficulty remembering what he/she just heard | ☐ (FP13:COGNI3) 0 | ☐ (FP13:COGNI3) 1 | ☐ (FP13:COGNI3) 2 | ☐ (FP13:COGNI3) 3 | ☐ (FP13:COGNI3) 4 |
| 4. | Difficulty thinking quickly | ☐ (FP13:COGNI4) 0 | ☐ (FP13:COGNI4) 1 | ☐ (FP13:COGNI4) 2 | ☐ (FP13:COGNI4) 3 | ☐ (FP13:COGNI4) 4 |
| 5. | Trouble remembering what he/she was just thinking | ☐ (FP13:COGNI5) 0 | ☐ (FP13:COGNI5) 1 | ☐ (FP13:COGNI5) 2 | ☐ (FP13:COGNI5) 3 | ☐ (FP13:COGNI5) 4 |
| 6. | Trouble remembering more than one thing at a time | ☐ (FP13:COGNI6) 0 | ☐ (FP13:COGNI6) 1 | ☐ (FP13:COGNI6) 2 | ☐ (FP13:COGNI6) 3 | ☐ (FP13:COGNI6) 4 |

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| Comprehensive Sickle Cell Centers | **Pediatric Pain Questionnaire Teen Form (13-18)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PQCT:FORMDA (DD) / PQCT:FORMMO (MMM) / PQCT:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

What words would you use to describe your pain or hurt?

PQCT:PAINWRD

Using a metric ruler, measure the distance of the subject's mark from the left-hand anchor on the line of the paper form completed by the patient. In the box below, enter the number in millimeters. Measure to the nearest whole millimeter. A mark drawn exactly on the left-hand anchor (No pain) should be entered as 0 and a mark drawn exactly on the right-hand anchor should be entered as 100 (Severe Pain).

Now: PQCT:PAINNOW

This Week: PQCT:PAINWK

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Pediatric Pain Questionnaire Parent of Teen Form (13-18)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: PQPT:FORMDA (DD) / PQPT:FORMMO (MMM) / PQPT:FORMYR (YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

What words would you use to describe your child's pain or hurt?

PQPT:PAINWRD

Using a metric ruler, measure the distance of the parent's mark from the left-hand anchor on the line of the paper form completed by the parent. In the box below, enter the number in millimeters. Measure to the nearest whole millimeter. A mark drawn exactly on the left-hand anchor (No pain) should be entered as 0 and a mark drawn exactly on the right-hand anchor should be entered as 100 (Severe Pain).

Now: PQPT:PAINNOW

Past Week: PQPT:PAINWK

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| Comprehensive Sickle Cell Centers | **SF-36 Health Survey** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: SF36:FORMDA / SF36:FORMMO / SF36:FORMYR (DD / MMM / YYYY) | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.**

Answer every question by selecting the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: [Click on the box that best describes your answer.]

| Excellent | Very Good | Good | Fair | Poor |
|---|---|---|---|---|
| ☐ (SF36:SFQ1) | ☐ (SF36:SFQ1) | ☐ (SF36:SFQ1) | ☐ (SF36:SFQ1) | ☐ (SF36:SFQ1) |

2. Compared to one year ago, how would you rate your health in general now?

| Much better now than one year ago | Somewhat better now than one year ago | About the same as one year ago | Somewhat worse now than one year ago | Much worse now than one year ago |
|---|---|---|---|---|
| ☐ (SF36:SFQ2) | ☐ (SF36:SFQ2) | ☐ (SF36:SFQ2) | ☐ (SF36:SFQ2) | ☐ (SF36:SFQ2) |

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Select an option on each line.]

| | | Yes, limited a lot | Yes, limited a little | No, not limited at all |
|---|---|---|---|---|
| a. | Vigorous Activities, such as running, lifting heavy objects, participating in strenuous sports | ☐ (SF36:SFQ3A) | ☐ (SF36:SFQ3A) | ☐ (SF36:SFQ3A) |
| b. | Moderate Activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | ☐ (SF36:SFQ3B) | ☐ (SF36:SFQ3B) | ☐ (SF36:SFQ3B) |
| c. | Lifting or carrying groceries | ☐ (SF36:SFQ3C) | ☐ (SF36:SFQ3C) | ☐ (SF36:SFQ3C) |
| d. | Climbing several flights of stairs | ☐ (SF36:SFQ3D) | ☐ (SF36:SFQ3D) | ☐ (SF36:SFQ3D) |
| e. | Climbing one flight of stairs | ☐ (SF36:SFQ3E) | ☐ (SF36:SFQ3E) | ☐ (SF36:SFQ3E) |
| f. | Bending, kneeling, or stooping | ☐ (SF36:SFQ3F) | ☐ (SF36:SFQ3F) | ☐ (SF36:SFQ3F) |
| g. | Walking more than a mile | ☐ (SF36:SFQ3G) | ☐ (SF36:SFQ3G) | ☐ (SF36:SFQ3G) |
| h. | Walking several hundred yards | ☐ (SF36:SFQ3H) | ☐ (SF36:SFQ3H) | ☐ (SF36:SFQ3H) |
| i. | Walking one hundred yards | ☐ (SF36:SFQ3I) | ☐ (SF36:SFQ3I) | ☐ (SF36:SFQ3I) |
| j. | Bathing or dressing yourself | ☐ (SF36:SFQ3J) | ☐ (SF36:SFQ3J) | ☐ (SF36:SFQ3J) |

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|

| | | | | | | |
|---|---|---|---|---|---|---|
| a. | Cut down on the amount of time you spent on work or other activities | ☐ (SF36:SFQ4A) | ☐ (SF36:SFQ4A) | ☐ (SF36:SFQ4A) | ☐ (SF36:SFQ4A) | ☐ (SF36:SFQ4A) |
| b. | Accomplished less than you would like | ☐ (SF36:SFQ4B) | ☐ (SF36:SFQ4B) | ☐ (SF36:SFQ4B) | ☐ (SF36:SFQ4B) | ☐ (SF36:SFQ4B) |
| c. | Were limited in the kind of work or other activities | ☐ (SF36:SFQ4C) | ☐ (SF36:SFQ4C) | ☐ (SF36:SFQ4C) | ☐ (SF36:SFQ4C) | ☐ (SF36:SFQ4C) |
| d. | Had difficulty performing the work or other activities (for example, it took extra effort) | ☐ (SF36:SFQ4D) | ☐ (SF36:SFQ4D) | ☐ (SF36:SFQ4D) | ☐ (SF36:SFQ4D) | ☐ (SF36:SFQ4D) |

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

| | | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|---|
| a. | Cut down on the amount of time you spent on work or other activities | ☐ (SF36:SFQ5A) | ☐ (SF36:SFQ5A) | ☐ (SF36:SFQ5A) | ☐ (SF36:SFQ5A) | ☐ (SF36:SFQ5A) |
| b. | Accomplished less than you would like | ☐ (SF36:SFQ5B) | ☐ (SF36:SFQ5B) | ☐ (SF36:SFQ5B) | ☐ (SF36:SFQ5B) | ☐ (SF36:SFQ5B) |
| c. | Did work or activities less carefully than usual | ☐ (SF36:SFQ5C) | ☐ (SF36:SFQ5C) | ☐ (SF36:SFQ5C) | ☐ (SF36:SFQ5C) | ☐ (SF36:SFQ5C) |

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

| Not at all | Slightly | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|
| ☐ (SF36:SFQ6) | ☐ (SF36:SFQ6) | ☐ (SF36:SFQ6) | ☐ (SF36:SFQ6) | ☐ (SF36:SFQ6) |

7. How much bodily pain have you had during the past 4 weeks?

| None | Very Mild | Mild | Moderate | Severe | Very Severe |
|---|---|---|---|---|---|
| ☐ (SF36:SFQ7) | ☐ (SF36:SFQ7) | ☐ (SF36:SFQ7) | ☐ (SF36:SFQ7) | ☐ (SF36:SFQ7) | ☐ (SF36:SFQ7) |

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

| Not at all | A little bit | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|
| ☐ (SF36:SFQ8) | ☐ (SF36:SFQ8) | ☐ (SF36:SFQ8) | ☐ (SF36:SFQ8) | ☐ (SF36:SFQ8) |

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

   How much of the time during the past 4 weeks...

| | | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|---|
| a. | Did you feel full of life? | ☐ (SF36:SFQ9A) | ☐ (SF36:SFQ9A) | ☐ (SF36:SFQ9A) | ☐ (SF36:SFQ9A) | ☐ (SF36:SFQ9A) |
| b. | Have you been very nervous? | ☐ (SF36:SFQ9B) | ☐ (SF36:SFQ9B) | ☐ (SF36:SFQ9B) | ☐ (SF36:SFQ9B) | ☐ (SF36:SFQ9B) |

| | | | | | | |
|---|---|---|---|---|---|---|
| c. | Have you felt so down in the dumps that nothing could cheer you up? | ☐ (SF36:SFQ9C) | ☐ (SF36:SFQ9C) | ☐ (SF36:SFQ9C) | ☐ (SF36:SFQ9C) | ☐ (SF36:SFQ9C) |
| d. | Have you felt calm and peaceful? | ☐ (SF36:SFQ9D) | ☐ (SF36:SFQ9D) | ☐ (SF36:SFQ9D) | ☐ (SF36:SFQ9D) | ☐ (SF36:SFQ9D) |
| e. | Did you have a lot of energy? | ☐ (SF36:SFQ9E) | ☐ (SF36:SFQ9E) | ☐ (SF36:SFQ9E) | ☐ (SF36:SFQ9E) | ☐ (SF36:SFQ9E) |
| f. | Have you felt downhearted and depressed? | ☐ (SF36:SFQ9F) | ☐ (SF36:SFQ9F) | ☐ (SF36:SFQ9F) | ☐ (SF36:SFQ9F) | ☐ (SF36:SFQ9F) |
| g. | Did you feel worn out? | ☐ (SF36:SFQ9G) | ☐ (SF36:SFQ9G) | ☐ (SF36:SFQ9G) | ☐ (SF36:SFQ9G) | ☐ (SF36:SFQ9G) |
| h. | Have you been happy? | ☐ (SF36:SFQ9H) | ☐ (SF36:SFQ9H) | ☐ (SF36:SFQ9H) | ☐ (SF36:SFQ9H) | ☐ (SF36:SFQ9H) |
| i. | Did you feel tired? | ☐ (SF36:SFQ9I) | ☐ (SF36:SFQ9I) | ☐ (SF36:SFQ9I) | ☐ (SF36:SFQ9I) | ☐ (SF36:SFQ9I) |

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

| All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|
| ☐ (SF36:SFQ10) | ☐ (SF36:SFQ10) | ☐ (SF36:SFQ10) | ☐ (SF36:SFQ10) | ☐ (SF36:SFQ10) |

11. How TRUE or FALSE is each of the following statements for you?

| | | Definitely true | Mostly true | Don't Know | Mostly false | Definitely false |
|---|---|---|---|---|---|---|
| a. | I seem to get sick a little easier than other people | ☐ (SF36:SFQ11A) | ☐ (SF36:SFQ11A) | ☐ (SF36:SFQ11A) | ☐ (SF36:SFQ11A) | ☐ (SF36:SFQ11A) |
| b. | I am as healthy as anybody I know | ☐ (SF36:SFQ11B) | ☐ (SF36:SFQ11B) | ☐ (SF36:SFQ11B) | ☐ (SF36:SFQ11B) | ☐ (SF36:SFQ11B) |
| c. | I expect my health to get worse | ☐ (SF36:SFQ11C) | ☐ (SF36:SFQ11C) | ☐ (SF36:SFQ11C) | ☐ (SF36:SFQ11C) | ☐ (SF36:SFQ11C) |
| d. | My health is excellent | ☐ (SF36:SFQ11D) | ☐ (SF36:SFQ11D) | ☐ (SF36:SFQ11D) | ☐ (SF36:SFQ11D) | ☐ (SF36:SFQ11D) |

Submit Query | Cancel | Print

| Comprehensive Sickle Cell Centers | **Short-Form Patient Satisfaction Questionnaire (PSQ-18)** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: SFPS:FORMDA / SFPS:FORMMO / SFPS:FORMYR<br>DD MMM YYYY | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

## These next questions are about how you feel about the medical care you receive.

On the following pages are some things people say about medical care. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received.

How strongly do you AGREE or DISAGREE with each of the following statements?

**(Select One on Each Line)**

| | | Strongly Agree | Agree | Uncertain | Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|
| 1. | Doctors are good about explaining the reason for medical tests | ☐ (SFPS:PSQ1) 1 | ☐ (SFPS:PSQ1) 2 | ☐ (SFPS:PSQ1) 3 | ☐ (SFPS:PSQ1) 4 | ☐ (SFPS:PSQ1) 5 |
| 2. | I think my doctor's office has everything | ☐ (SFPS:PSQ2) 1 | ☐ (SFPS:PSQ2) 2 | ☐ (SFPS:PSQ2) 3 | ☐ (SFPS:PSQ2) 4 | ☐ (SFPS:PSQ2) 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | needed to provide complete medical care | | | | | |
| 3. | The medical care I have been receiving is just about perfect | ☐ (SFPS:PSQ3) 1 | ☐ (SFPS:PSQ3) 2 | ☐ (SFPS:PSQ3) 3 | ☐ (SFPS:PSQ3) 4 | ☐ (SFPS:PSQ3) 5 |
| 4. | Sometimes doctors make me wonder if their diagnosis is correct | ☐ (SFPS:PSQ4) 1 | ☐ (SFPS:PSQ4) 2 | ☐ (SFPS:PSQ4) 3 | ☐ (SFPS:PSQ4) 4 | ☐ (SFPS:PSQ4) 5 |
| 5. | I feel confident that I can get the medical care I need without being set back financially | ☐ (SFPS:PSQ5) 1 | ☐ (SFPS:PSQ5) 2 | ☐ (SFPS:PSQ5) 3 | ☐ (SFPS:PSQ5) 4 | ☐ (SFPS:PSQ5) 5 |
| 6. | When I go for medical care, they are careful to check everything when | ☐ (SFPS:PSQ6) 1 | ☐ (SFPS:PSQ6) 2 | ☐ (SFPS:PSQ6) 3 | ☐ (SFPS:PSQ6) 4 | ☐ (SFPS:PSQ6) 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | treating and examining me | | | | | |
| 7. | I have to pay for more of my medical care than I can afford | ☐ (SFPS:PSQ7) 1 | ☐ (SFPS:PSQ7) 2 | ☐ (SFPS:PSQ7) 3 | ☐ (SFPS:PSQ7) 4 | ☐ (SFPS:PSQ7) 5 |
| 8. | I have easy access to the medical specialists I need | ☐ (SFPS:PSQ8) 1 | ☐ (SFPS:PSQ8) 2 | ☐ (SFPS:PSQ8) 3 | ☐ (SFPS:PSQ8) 4 | ☐ (SFPS:PSQ8) 5 |
| 9. | Where I get medical care, people have to wait too long for emergency treatment | ☐ (SFPS:PSQ9) 1 | ☐ (SFPS:PSQ9) 2 | ☐ (SFPS:PSQ9) 3 | ☐ (SFPS:PSQ9) 4 | ☐ (SFPS:PSQ9) 5 |
| 10. | Doctors act too businesslike and impersonal toward me | ☐ (SFPS:PSQ10) 1 | ☐ (SFPS:PSQ10) 2 | ☐ (SFPS:PSQ10) 3 | ☐ (SFPS:PSQ10) 4 | ☐ (SFPS:PSQ10) 5 |
| 11. | My doctors treat me in a very friendly and courteous manner | ☐ (SFPS:PSQ11) 1 | ☐ (SFPS:PSQ11) 2 | ☐ (SFPS:PSQ11) 3 | ☐ (SFPS:PSQ11) 4 | ☐ (SFPS:PSQ11) 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 12. | Those who provide my medical care sometimes hurry too much when they treat me | ☐ (SFPS:PSQ12) 1 | ☐ (SFPS:PSQ12) 2 | ☐ (SFPS:PSQ12) 3 | ☐ (SFPS:PSQ12) 4 | ☐ (SFPS:PSQ12) 5 |
| 13. | Doctors sometimes ignore what I tell them | ☐ (SFPS:PSQ13) 1 | ☐ (SFPS:PSQ13) 2 | ☐ (SFPS:PSQ13) 3 | ☐ (SFPS:PSQ13) 4 | ☐ (SFPS:PSQ13) 5 |
| 14. | I have some doubts about the ability of the doctors who treat me | ☐ (SFPS:PSQ14) 1 | ☐ (SFPS:PSQ14) 2 | ☐ (SFPS:PSQ14) 3 | ☐ (SFPS:PSQ14) 4 | ☐ (SFPS:PSQ14) 5 |
| 15. | Doctors usually spend plenty of time with me | ☐ (SFPS:PSQ15) 1 | ☐ (SFPS:PSQ15) 2 | ☐ (SFPS:PSQ15) 3 | ☐ (SFPS:PSQ15) 4 | ☐ (SFPS:PSQ15) 5 |
| 16. | I find it hard to get an appointment for medical care right away | ☐ (SFPS:PSQ16) 1 | ☐ (SFPS:PSQ16) 2 | ☐ (SFPS:PSQ16) 3 | ☐ (SFPS:PSQ16) 4 | ☐ (SFPS:PSQ16) 5 |
| 17. | I am dissatisfied with some things about | ☐ (SFPS:PSQ17) 1 | ☐ (SFPS:PSQ17) 2 | ☐ (SFPS:PSQ17) 3 | ☐ (SFPS:PSQ17) 4 | ☐ (SFPS:PSQ17) 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | the medical care I receive | | | | | |
| 18. | I am able to get medical care whenever I need it | ☐ (SFPS:PSQ18) 1 | ☐ (SFPS:PSQ18) 2 | ☐ (SFPS:PSQ18) 3 | ☐ (SFPS:PSQ18) 4 | ☐ (SFPS:PSQ18) 5 |

Submit Query | Cancel | Print

| Comprehensive Sickle Cell Centers | **Annual Form Part I** | **Page: {section.pageNumber}** |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: AFDM:COMPDA / AFDM:COMPMO / AFDM:COMPYR (DD / MMM / YYYY)<br>Form Completed by: AFDM:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**This report covers the following period:**

Note: The period should begin with the day after the last Semi-Annual/Annual Form end date (or the day after enrollment, if this is the first Annual Form). The end date is twelve months from the start date.

**Start date:** AFDM:STARTDA / AFDM:STARTMO / AFDM:STARTYR (DD / MMM / YYYY) **through** **End date:** AFDM:ENDDA / AFDM:ENDMO / AFDM:ENDYR (DD / MMM / YYYY)

How much data was collected?

- ☐ (AFDM:DATA) All data available for this reporting period
- ☐ (AFDM:DATA) No data available for this reporting period (patient not seen)[1]
- ☐ (AFDM:DATA) Partial data available for this reporting period[2]

During this report period, how many scheduled visits for sickle cell did this patient attend, including today? AFDM:NUMVIS

Weight: AFDM:WT ☐ (AFDM:WTUNIT) lb ☐ (AFDM:WTUNIT) kg

Height: AFDM:HT ☐ (AFDM:HTUNIT) in ☐ (AFDM:HTUNIT) cm

*See guidelines for specific instructions.*

Date of weight measurement: AFDM:WTDA / AFDM:WTMO / AFDM:WTYR (DD / MMM / YYYY)

Date of height measurement: AFDM:HTDA / AFDM:HTMO / AFDM:HTYR (DD / MMM / YYYY)

Has the patient participated in a research study during the report period? ☐ (AFDM:CURSTUD) Yes ☐ (AFDM:CURSTUD) No

*[If Yes]* **Check all that apply**

- ☐ (AFDM:ARGINE) **Arginine**
- ☐ (AFDM:NEURO) **Neuropsych**
- ☐ (AFDM:HUMAG) **Hydroxyurea-Magnesium**
- ☐ (AFDM:PRIAP) **Priapism** (multi-center)
- ☐ (AFDM:DEXAM) **Dexamethasone**
- ☐ (AFDM:DECIT) **Decitabine**
- ☐ (AFDM:METHA) **Methadone**
- ☐ (AFDM:WTCN) **Within-Center Study** (specify) AFDM:WTCNSP
- ☐ (AFDM:OTHST) **Other Study** (specify) AFDM:OTHSTSP

[1]All other forms for this Semi-Annual/Annual Form Visit should not be created or entered into EDC.
[2]Create and enter only the forms that were completed for this Semi-Annual/Annual Visit.

Comments for page:

AFDM:COMTXT

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| Comprehensive Sickle Cell Centers | Annual Form Part I Transfusions | Page: {section.pageNumber} |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: AFTR:COMPDA (DD) / AFTR:COMPMO (MMM) / AFTR:COMPYR (YYYY)<br>Form Completed by: AFTR:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

This report covers the following period: **Start date:** {STARTDT} **through** **End date:** {ENDDT}

**Has this patient received a transfusion *during the report period*?** ☐ (AFTR:TRANPY) Yes ☐ (AFTR:TRANPY) No ☐ (AFTR:TRANPY) Unknown

**If yes, how would you describe this patient's transfusion history *during the report period*?**

Number of transfusions: ☐ (AFTR:TRANHX) 1-5 ☐ (AFTR:TRANHX) 6-20 ☐ (AFTR:TRANHX) 21-99 ☐ (AFTR:TRANHX) 100+

**Has iron overload been assessed *during the report period*?** ☐ (AFTR:IRONOV) Yes ☐ (AFTR:IRONOV) No ☐ (AFTR:IRONOV) Unknown

**If yes**, enter results of the most recent assessments:

| | Yes | No | Unknown | Result | Date |
|---|---|---|---|---|---|
| Liver Biopsy: | ☐ (AFTR:LIVER) | ☐ (AFTR:LIVER) | ☐ (AFTR:LIVER) | AFTR:LIVRES mg Fe/g Dry Weight | AFTR:LIVRDA (DD) / AFTR:LIVRMO (MMM) / AFTR:LIVRYR (YYYY) |
| Ferritin: | ☐ (AFTR:FERRIT) | ☐ (AFTR:FERRIT) | ☐ (AFTR:FERRIT) | AFTR:FERRES µg/L | AFTR:FERRDA (DD) / AFTR:FERRMO (MMM) / AFTR:FERRYR (YYYY) |
| SQUID: | ☐ (AFTR:SQUID) | ☐ (AFTR:SQUID) | ☐ (AFTR:SQUID) | AFTR:SQUIRES mg Fe/g Dry Weight | AFTR:SQUIDDA (DD) / AFTR:SQUIDMO (MMM) / AFTR:SQUIDYR (YYYY) |

**Has this patient received iron chelation therapy *during the report period*?** ☐ (AFTR:IRONCH) Yes ☐ (AFTR:IRONCH) No ☐ (AFTR:IRONCH) Unknown

**If yes, check all that apply:** ☐ (AFTR:ORAL)Desferal ☐ (AFTR:IRONTH)Oral (i.e., Exjade/deferasirox) ☐ (AFTR:UNKNOWN) Unknown

**Has this patient had RBC antibodies documented *during the report period*?** ☐ (AFTR:RBCDOC) Yes ☐ (AFTR:RBCDOC) No ☐ (AFTR:RBCDOC) Unknown

*If yes, check all that were present/positive:*

| | | | | | |
|---|---|---|---|---|---|
| ☐ (AFTR:LC) c | ☐ (AFTR:UE) E | ☐ (AFTR:FYB) Fyb | ☐ (AFTR:LK) k | ☐ (AFTR:LEB) Leb | ☐ (AFTR:COLD) Cold antibody |
| ☐ (AFTR:UC) C | ☐ (AFTR:LE) e | ☐ (AFTR:JKA) Jka | ☐ (AFTR:UK) K | ☐ (AFTR:M) M | ☐ (AFTR:RBCUNK) Unknown |
| ☐ (AFTR:D) D | ☐ (AFTR:FYA) Fya | ☐ (AFTR:JKB) Jkb | ☐ (AFTR:LEA) Lea | ☐ (AFTR:WARM) Warm autoantibody | ☐ (AFTR:RBCOTH) Other |

Comments for page:

AFTR:COMTXT

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| Comprehensive Sickle Cell Centers | Annual Form Part I Medications/Lab Tests | Page: {section.pageNumber} |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: AFMD:COMPDA / AFMD:COMPMO / AFMD:COMPYR (DD / MMM / YYYY)<br>Form Completed by: AFMD:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

This report covers the following period: **Start date:** {STARTDT} through **End date:** {ENDDT}

**Selected Medications**

Record any of the listed medications used by the patient during the report period.

| Medications | Yes | No | Unk | Specify | Start Date DD/MMM/YYYY | Previously Reported | End Date DD/MMM/YYYY | Ongoing |
|---|---|---|---|---|---|---|---|---|
| Hydroxyurea | ☐ (AFMD:HYDROX) | ☐ (AFMD:HYDROX) | ☐ (AFMD:HYDROX) | | AFMD:HYDSTDA / AFMD:HYDSTMO / AFMD:HYDSTYR | ☐ (AFMD:HYDPR) | AFMD:HYDENDA / AFMD:HYDENMO / AFMD:HYDENYR | ☐ (AFMD:HYDONGO) |
| Other Anti-Sickling Agents | ☐ (AFMD:ANTISIC) | ☐ (AFMD:ANTISIC) | ☐ (AFMD:ANTISIC) | AFMD:ATSICS | AFMD:ANTSTDA / AFMD:ANTSTMO / AFMD:ANTSTYR | ☐ (AFMD:ANTPR) | AFMD:ANTENDA / AFMD:ANTENMO / AFMD:ANTENYR | ☐ (AFMD:ANTONGO) |
| Prophylactic Penicillin, other Prophylactic Antibiotics | ☐ (AFMD:PROPH) | ☐ (AFMD:PROPH) | ☐ (AFMD:PROPH) | | AFMD:PROSTDA / AFMD:PROSTMO / AFMD:PROSTYR | ☐ (AFMD:PROPR) | AFMD:PROENDA / AFMD:PROENMO / AFMD:PROENYR | ☐ (AFMD:PROONGO) |
| Desferal | ☐ (AFMD:DESFER) | ☐ (AFMD:DESFER) | ☐ (AFMD:DESFER) | | AFMD:DESSTDA / AFMD:DESSTMO / AFMD:DESSTYR | ☐ (AFMD:DESPR) | AFMD:DESENDA / AFMD:DESENMO / AFMD:DESENYR | ☐ (AFMD:DESONGO) |
| Oral iron chelator (Exjade/deferasirox) | ☐ (AFMD:IRONCH) | ☐ (AFMD:IRONCH) | ☐ (AFMD:IRONCH) | | AFMD:IROSTDA / AFMD:IROSTMO / AFMD:IROSTYR | ☐ (AFMD:IROPR) | AFMD:IROENDA / AFMD:IROENMO / AFMD:IROENYR | ☐ (AFMD:IROONGO) |
| Oxygen at home | ☐ (AFMD:OXYGEN) | ☐ (AFMD:OXYGEN) | ☐ (AFMD:OXYGEN) | | AFMD:OXYSTDA / AFMD:OXYSTMO / AFMD:OXYSTYR | ☐ (AFMD:OXYPR) | AFMD:OXYENDA / AFMD:OXYENMO / AFMD:OXYENYR | ☐ (AFMD:OXYONGO) |
| Antidepressants | ☐ (AFMD:ANTDEP) | ☐ (AFMD:ANTDEP) | ☐ (AFMD:ANTDEP) | AFMD:ANTDEPS | AFMD:DEPSTDA / AFMD:DEPSTMO / AFMD:DEPSTYR | ☐ (AFMD:DEPPR) | AFMD:DEPENDA / AFMD:DEPENMO / AFMD:DEPENYR | ☐ (AFMD:DEPONGO) |
| Anticonvulsants | ☐ (AFMD:ANTCON) | ☐ (AFMD:ANTCON) | ☐ (AFMD:ANTCON) | AFMD:ANTCONS | AFMD:CONSTDA / AFMD:CONSTMO / AFMD:CONSTYR | ☐ (AFMD:CONPR) | AFMD:CONENDA / AFMD:CONENMO / AFMD:CONENYR | ☐ (AFMD:CONONGO) |
| Narcotics Daily, 30+ days | ☐ (AFMD:NARCO) | ☐ (AFMD:NARCO) | ☐ (AFMD:NARCO) | | AFMD:NARSTDA / AFMD:NARSTMO / AFMD:NARSTYR | ☐ (AFMD:NARPR) | AFMD:NARENDA / AFMD:NARENMO / AFMD:NARENYR | ☐ (AFMD:NARONGO) |
| Other Alternative Therapies (herbal treatments, antioxidants, vitamin C, etc.) | ☐ (AFMD:ALTER) | ☐ (AFMD:ALTER) | ☐ (AFMD:ALTER) | AFMD:ALTERS | AFMD:ALTSTDA / AFMD:ALTSTMO / AFMD:ALTSTYR | ☐ (AFMD:ALTPR) | AFMD:ALTENDA / AFMD:ALTENMO / AFMD:ALTENYR | ☐ (AFMD:ALTONGO) |

**Selected Lab Tests**

*Please record the most recent blood counts (if available) from during the report period. The values MUST be from when the patient was an outpatient and had not been transfused or hospitalized for at least 2 months. The patient should have also not been experiencing any other clinical event that would influence these labs (i.e., parvovirus) at the time the labs were drawn.*

**Does this patient have labs recorded during the report period that meet the criteria described above?** ☐ (AFMD:CHTRLAB)Yes ☐ (AFMD:CHTRLAB)No

**If Yes,**

| Test | Most Recent Specimen Date DD / MMM / YYYY | Result | Comment |
|---|---|---|---|
| Hgb | AFMD:HGBDA / AFMD:HGBMO / AFMD:HGBYR | AFMD:HGBRS (gm/dL) | AFMD:HGBCM |
| WBC | AFMD:WBCDA / AFMD:WBCMO / AFMD:WBCYR | AFMD:WBCRS ($x10^9$/L) | AFMD:WBCCM |
| Platelet | AFMD:PLATEDA / AFMD:PLATEMO / AFMD:PLATEYR | AFMD:PLATERS ($x10^9$/L) | AFMD:PLATECM |

Comments for page:

AFMD:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Annual Form Part I<br>Selected Diagnostic Tests | Page: {section.pageNumber} |
|---|---|---|
| Collaborative Data Project | Date Form Completed: AFSD:COMPDA / AFSD:COMPMO / AFSD:COMPYR (DD / MMM / YYYY)<br>Form Completed by: AFSD:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

This report covers the following period: **Start date:** {STARTDT} through **End date:** {ENDDT}

Record the results of the following diagnostic tests performed **most recently** on this patient *during the report period.*

| Test | Performed | | Most Recent Test Date | Result | | | | Comments |
|---|---|---|---|---|---|---|---|---|
| | Yes | No | dd/mmm/yyyy | Normal | New Abnormal | Repeated Abnormal | Equivocal | (reason for test, etc.) |
| MRI, Head | (AFSD:MRIPER) | (AFSD:MRIPER) | AFSD:MRIDA / AFSD:MRIMO / AFSD:MRIYR | (AFSD:MRIRES) | (AFSD:MRIRES) | (AFSD:MRIRES) | (AFSD:MRIRES) | AFSD:MRICOM |
| MRA, Head | (AFSD:MRAPER) | (AFSD:MRAPER) | AFSD:MRADA / AFSD:MRAMO / AFSD:MRAYR | (AFSD:MRARES) | (AFSD:MRARES) | (AFSD:MRARES) | (AFSD:MRARES) | AFSD:MRACOM |
| Transcranial Doppler (TCD) | (AFSD:TCDPER) | (AFSD:TCDPER) | AFSD:TCDDA / AFSD:TCDMO / AFSD:TCDYR | (AFSD:TCDRES) | (AFSD:TCDRES) | (AFSD:TCDRES) | (AFSD:TCDRES) | AFSD:TCDCOM |
| Echocardiogram | (AFSD:ECHOPER) | (AFSD:ECHOPER) | AFSD:ECHODA / AFSD:ECHOMO / AFSD:ECHOYR | (AFSD:ECHORES) | (AFSD:ECHORES) | (AFSD:ECHORES) | (AFSD:ECHORES) | AFSD:ECHOCOM |
| Pulmonary Function Testing | (AFSD:PFTPER) | (AFSD:PFTPER) | AFSD:PFTDA / AFSD:PFTMO / AFSD:PFTYR | (AFSD:PFTRES) | (AFSD:PFTRES) | (AFSD:PFTRES) | (AFSD:PFTRES) | AFSD:PFTCOM |
| EKG | (AFSD:EKGPER) | (AFSD:EKGPER) | AFSD:EKGDA / AFSD:EKGMO / AFSD:EKGYR | (AFSD:EKGRES) | (AFSD:EKGRES) | (AFSD:EKGRES) | (AFSD:EKGRES) | AFSD:EKGCOM |

Press the "Add" button to record the results of any diagnostic tests performed **multiple times** on this patient *during the report period.*

| Test | Test Date | Result | | | | Comments | |
|---|---|---|---|---|---|---|---|
| | dd/mmm/yyyy | Normal | New Abnormal | Repeated Abnormal | Equivocal | (reason for test, etc.) | |
| AFDT:TEST | AFDT:TESTDA / AFDT:TESTMO / AFDT:TESTYR | (AFDT:RESULT) | (AFDT:RESULT) | (AFDT:RESULT) | (AFDT:RESULT) | AFDT:COMM | Delete Entry |

Add Entry

Comments for page:

AFSD:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Annual Form Part I<br>Surgical Procedures | Page: {section.pageNumber} |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: AFSG:COMPDA / AFSG:COMPMO / AFSG:COMPYR (DD / MMM / YYYY)<br>Form Completed by: AFSG:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

This report covers the following period: **Start date:** {STARTDT} through **End date:** {ENDDT}

## Surgical History

**To the best of your knowledge, has this patient had any of the following surgical procedures during the report period?**

*(If the patient has had the same surgery more than once, please record the most recent procedure.)*

| | Yes | Procedure Date (dd/mmm/yyyy) | No | Unknown |
|---|---|---|---|---|
| Tonsillectomy/Adenoidectomy ☐ (AFSG:TONSLFR) 1 Time ☐ (AFSG:TONSLFR) >1 Time | ☐ (AFSG:TONSL) | AFSG:SG1DA / AFSG:SG1MO / AFSG:SG1YR | ☐ (AFSG:TONSL) | ☐ (AFSG:TONSL) |
| Splenectomy | ☐ (AFSG:SPLEN) | AFSG:SG2DA / AFSG:SG2MO / AFSG:SG2YR | ☐ (AFSG:SPLEN) | ☐ (AFSG:SPLEN) |
| Cholecystectomy | ☐ (AFSG:CHOL) | AFSG:SG3DA / AFSG:SG3MO / AFSG:SG3YR | ☐ (AFSG:CHOL) | ☐ (AFSG:CHOL) |
| Hip Core Procedure | ☐ (AFSG:HIPCO) | AFSG:SG4DA / AFSG:SG4MO / AFSG:SG4YR | ☐ (AFSG:HIPCO) | ☐ (AFSG:HIPCO) |
| Hip Replacement ☐ (AFSG:HIPRFR) 1 Time ☐ (AFSG:HIPRFR) >1 Time | ☐ (AFSG:HIPR) | AFSG:SG5DA / AFSG:SG5MO / AFSG:SG5YR | ☐ (AFSG:HIPR) | ☐ (AFSG:HIPR) |
| Laser Procedure of the Eye(s) | ☐ (AFSG:LASER) | AFSG:SG6DA / AFSG:SG6MO / AFSG:SG6YR | ☐ (AFSG:LASER) | ☐ (AFSG:LASER) |

| | | | | |
|---|---|---|---|---|
| Vitrectomy | ☐ (AFSG:VITRE) | AFSG:SG7DA / AFSG:SG7MO / AFSG:SG7YR | ☐ (AFSG:VITRE) | ☐ (AFSG:VITRE) |
| Insertion of a Permanent Indwelling Line | ☐ (AFSG:PLINE) | AFSG:SG8DA / AFSG:SG8MO / AFSG:SG8YR | ☐ (AFSG:PLINE) | ☐ (AFSG:PLINE) |
| Removal of a Permanent Indwelling Line | ☐ (AFSG:RPLINE) | AFSG:SG9DA / AFSG:SG9MO / AFSG:SG9YR | ☐ (AFSG:RPLINE) | ☐ (AFSG:RPLINE) |
| Other, specify AFSG:OTH1SP | | AFSG:OTH1DA / AFSG:OTH1MO / AFSG:OTH1YR | | |
| Other, specify AFSG:OTH2SP | | AFSG:OTH2DA / AFSG:OTH2MO / AFSG:OTH2YR | | |
| Other, specify AFSG:OTH3SP | | AFSG:OTH3DA / AFSG:OTH3MO / AFSG:OTH3YR | | |

Comments for page:

AFSG:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Annual Form Part I<br>Medical Conditions** | **Pages: 6-7 of 9** |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: MCON:COMPDA / MCON:COMPMO / MCON:COMPYR (DD / MMM / YYYY)<br>Form Completed by: MCON:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

This report covers the following period: **Start date:** {STARTDT} through **End date:** {ENDDT}

**Has this patient had or been diagnosed with a new or recurrent episode of ... during the report period?**

| | | | | |
|---|---|---|---|---|
| ☐ (MCON:COND1) | Yes | ☐ (MCON:COND1) | No | (Anemia) Aplastic Episode* |
| ☐ (MCON:COND2) | Yes | ☐ (MCON:COND2) | No | (Anemia) Immune and Non-immune Hemolysis/Hyperhemolysis |
| ☐ (MCON:COND3) | Yes | ☐ (MCON:COND3) | No | (Anemia) Other Anemia |
| ☐ (MCON:COND4) | Yes | ☐ (MCON:COND4) | No | (Anemia) Acute Splenic Sequestration* |
| ☐ (MCON:COND5) | Yes | ☐ (MCON:COND5) | No | (Cardiac) Cardiomyopathy |
| ☐ (MCON:COND6) | Yes | ☐ (MCON:COND6) | No | (Cardiac) Hypertension |
| ☐ (MCON:COND7) | Yes | ☐ (MCON:COND7) | No | (Cardiac) Mitral Valve Prolapse |
| ☐ (MCON:COND8) | Yes | ☐ (MCON:COND8) | No | (Cardiac) Myocardial Infarction* |
| ☐ (MCON:COND9) | Yes | ☐ (MCON:COND9) | No | (CNS) Seizure* |
| ☐ (MCON:COND10) | Yes | ☐ (MCON:COND10) | No | (CNS) Stroke-Hemorrhagic* |
| ☐ (MCON:COND11) | Yes | ☐ (MCON:COND11) | No | (CNS) Stroke-Infarctive* |
| ☐ (MCON:COND12) | Yes | ☐ (MCON:COND12) | No | (CNS) Stroke-Silent Cerebral Infarct* |
| ☐ (MCON:COND13) | Yes | ☐ (MCON:COND13) | No | (CNS) Elevated Transcranial Doppler (TCD) Velocities* |
| ☐ (MCON:COND14) | Yes | ☐ (MCON:COND14) | No | (CNS) Transient Ischemic Attack (TIA)* |
| ☐ (MCON:COND15) | Yes | ☐ (MCON:COND15) | No | (GI/Hepatobiliary) Cholecystitis |
| ☐ (MCON:COND16) | Yes | ☐ (MCON:COND16) | No | (GI/Hepatobiliary) Cholelithiasis/Sludge |
| ☐ (MCON:COND17) | Yes | ☐ (MCON:COND17) | No | (GI/Hepatobiliary) Hepatic Sequestration* |
| ☐ (MCON:COND18) | Yes | ☐ (MCON:COND18) | No | (GI/Hepatobiliary) Intrahepatic Cholestasis* |
| ☐ (MCON:COND19) | Yes | ☐ (MCON:COND19) | No | (GI/Hepatobiliary) Pancreatitis |
| ☐ (MCON:COND20) | Yes | ☐ (MCON:COND20) | No | (GI/Hepatobiliary) Viral Hepatitis* |
| ☐ (MCON:COND21) | Yes | ☐ (MCON:COND21) | No | (Muscular, Skeletal, Skin) Avascular Necrosis* |
| ☐ (MCON:COND22) | Yes | ☐ (MCON:COND22) | No | (Muscular, Skeletal, Skin) Dactylitis (Hand Foot Syndrome) |
| ☐ (MCON:COND23) | Yes | ☐ (MCON:COND23) | No | (Muscular, Skeletal, Skin) Leg Ulcers |
| ☐ (MCON:COND24) | Yes | ☐ (MCON:COND24) | No | (Muscular, Skeletal, Skin) Osteomyelitis (Acute or Chronic)* |
| ☐ (MCON:COND25) | Yes | ☐ (MCON:COND25) | No | (Ocular) Retinopathy |
| ☐ (MCON:COND26) | Yes | ☐ (MCON:COND26) | No | (Pain) Acute Multi-organ Failure |
| ☐ (MCON:COND27) | Yes | ☐ (MCON:COND27) | No | (Pain) Neuropathy (Neuropathic Pain) |
| ☐ (MCON:COND28) | Yes | ☐ (MCON:COND28) | No | (Pain) Sickle Cell Pain |
| ☐ (MCON:COND29) | Yes | ☐ (MCON:COND29) | No | (Pulmonary) Acute Chest Syndrome* |
| ☐ (MCON:COND30) | Yes | ☐ (MCON:COND30) | No | (Pulmonary) Chronic Obstructive Lung Disease |

| | | | | |
|---|---|---|---|---|
| ☐ (MCON:COND31) | Yes | ☐ (MCON:COND31) | No | (Pulmonary) Chronic Restrictive Lung Disease |
| ☐ (MCON:COND32) | Yes | ☐ (MCON:COND32) | No | (Pulmonary) Pulmonary Embolism* |
| ☐ (MCON:COND33) | Yes | ☐ (MCON:COND33) | No | (Pulmonary) Pulmonary Hypertension* |
| ☐ (MCON:COND34) | Yes | ☐ (MCON:COND34) | No | (Pulmonary) Persistent Reactive Airways Disease (Asthma) |
| ☐ (MCON:COND35) | Yes | ☐ (MCON:COND35) | No | (Renal/Genitourinary) Acute Renal Failure* |
| ☐ (MCON:COND36) | Yes | ☐ (MCON:COND36) | No | (Renal/Genitourinary) Chronic Renal Insufficiency* |
| ☐ (MCON:COND37) | Yes | ☐ (MCON:COND37) | No | (Renal/Genitourinary) Hematuria* |
| ☐ (MCON:COND38) | Yes | ☐ (MCON:COND38) | No | (Renal/Genitourinary) Priapism* |
| ☐ (MCON:COND39) | Yes | ☐ (MCON:COND39) | No | (Renal/Genitourinary) Proteinuria/Nephrotic Syndrome* |
| ☐ (MCON:COND40) | Yes | ☐ (MCON:COND40) | No | (Renal/Genitourinary) Pyelonephritis |
| ☐ (MCON:COND41) | Yes | ☐ (MCON:COND41) | No | (Splenic) Splenic Infarction |
| ☐ (MCON:COND42) | Yes | ☐ (MCON:COND42) | No | (Splenic) Chronic Hypersplenism* |
| ☐ (MCON:COND43) | Yes | ☐ (MCON:COND43) | No | (Transfusions/Iron Overload) Transfusional Hemosiderosis |
| ☐ (MCON:COND44) | Yes | ☐ (MCON:COND44) | No | Bacteremia/Sepsis/Meningitis* |

**Note:** A supplemental CRF is required if a condition with an * is marked Yes.

Comments for page:

MCON:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Annual Form Part I<br>Encounter Summary | Page: {section.pageNumber} |
|---|---|---|
| Collaborative Data Project | Date Form Completed: AFSM:COMPDA / AFSM:COMPMO / AFSM:COMPYR<br>DD MMM YYYY<br>Form Completed by: AFSM:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

This report covers the following period: **Start date:** {STARTDT} through **End date:** {ENDDT}

**Encounter Summary-Acute Care Events (THIS IS NOT FOR ROUTINE SCHEDULED VISITS)**

Click the "Add" button for each encounter.

Delete Entry

| Date of Encounter | Admission Status | | Most Important Symptoms/Presenting Problems/Diagnoses: (up to 3) | |
|---|---|---|---|---|
| | Admitted to hospital? | | Symptom/Diagnosis #1: | AFES:DIAG1 |
| AFES:ENCDA / AFES:ENCMO / AFES:ENCYR<br>Day/Month/Year | | Date of discharge: | Other, specify: | AFES:DIAG1SP |
| | ☐ (AFES:PERFYN) Yes → | AFES:DISCDA / AFES:DISCMO / AFES:DISCYR Day/Month/Year | Symptom/Diagnosis #2: | AFES:DIAG2 |
| | | | Other; specify: | AFES:DIAG2SP |
| | ☐ (AFES:PERFYN) No → | AFES:VISTYP | Symptom/Diagnosis #3: | AFES:DIAG3 |
| | | | Other; specify: | AFES:DIAG3SP |

Add Entry

Comments for page:

AFSM:COMTXT

Submit Query Cancel Form Completion Help Print

| Comprehensive Sickle Cell Centers | **Annual Form Part I** | **Page: {section.pageNumber}** |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: AFPR:COMPDA / AFPR:COMPMO / AFPR:COMPYR (DD / MMM / YYYY)<br>Form Completed by: AFPR:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

This report covers the following period: **Start date:** {STARTDT} through **End date:** {ENDDT}

**For Provider use only:**

Based on social or psychological factors, or clinical attendance or scheduled visit compliance, would you exclude this patient from participation in a clinical trial?

- ☐ (AFPR:EXCLUDE) Would exclude, or probably would exclude
- ☐ (AFPR:EXCLUDE) Would not exclude, or probably would not exclude
- ☐ (AFPR:EXCLUDE) Not sure

Check only one:

- ☐ (AFPR:MEDINFO) Information for this medical history was obtained totally from chart abstraction and medical records.
- ☐ (AFPR:MEDINFO) Some information was provided by the patient (or parent/guardian of the patient).

**Please check the pages that include information provided by the patient (or parent/guardian of the patient):** *(check all that apply)*

- ☐ (AFPR:PAGE1) Page 1 specify: AFPR:PAGE1SP
- ☐ (AFPR:TRANHX) Transfusions (page 2)
- ☐ (AFPR:RBCANTI) RBC antibodies (page 2)
- ☐ (AFPR:SELMED) Selected Medications (page 3)
- ☐ (AFPR:LABTST) Selected Lab Tests (page 3)
- ☐ (AFPR:DIAGTST) Selected Diagnostic Tests (page 4)
- ☐ (AFPR:SURGPRO) Surgical Procedures(page 5)
- ☐ (AFPR:MEDCON) Medical Conditions (pages 6-7)
- ☐ (AFPR:ENCSUMM) Encounter Summary (page 8)

Comments for page:

AFPR:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Aplastic Episode | Anemia CRF Page 1 of 2 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by APL1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had an aplastic episode during the report period? APL1:EPISODE

If the subject has had more than 2 aplastic episodes during the report period, please explain why there were so many :

APL1:EXPLAIN

Delete Episode

Date of Event: APL2:EVENTDA / APL2:EVENTMO / APL2:EVENTYR

**DD** **MMM** **YYYY**

Baseline Hgb: APL2:BHGB g/dL Lowest Hgb: APL2:LHGB g/dL

Lowest absolute reticulocyte count: APL2:LARC / $mm^3$

**OR**

Lowest % Retic: APL2:LRETIC % Red Cell Count: APL2:REDC million

Was the subject transfused? ☐ (APL2:TRANSF)Yes ☐ (APL2:TRANSF)No

*If no and the Lowest hgb is* ≤ 4.0, please provide an explanation:

APL2:TRANSP

Was parvovirus B19 infection testing done?

☐ (APL2:DONE)Yes ☐ (APL2:DONE)No

**If Yes**, result(s): DNA → ☐ (APL2:DNARES) Positive ☐ (APL2:DNARES) Negative ☐ (APL2:DNARES) Not Done

Serology → ☐ (APL2:SERRES) Positive ☐ (APL2:SERRES) Negative ☐ (APL2:SERRES) Not Done

Was the patient on Hydroxyurea at the time of this episode? ☐ (APL2:HYDROX)Yes ☐ (APL2:HYDROX)No

Add Episode

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Acute Splenic Sequestration | Anemia CRF Page 2 of 2 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by ACU1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had an acute splenic sequestration during the report period? ACU1:EPISODE

Date clinical diagnosis was made: ACU2:DIAGDA / ACU2:DIAGMO / ACU2:DIAGYR
**DD** **MMM** **YYYY**

Delete Diagnosis

Baseline Hgb: ACU2:BHGB g/dL Lowest Hgb: ACU2:LHGB g/dL

Lowest platelet count: ACU2:PLAT x $10^3/mm^3$

Was the spleen palpable? ☐ (ACU2:SPLPALP)Yes ☐ (ACU2:SPLPALP)No

Was the spleen enlarged ≥ 2 cm from previous exam? ☐ (ACU2:SPLENL)Yes ☐ (ACU2:SPLENL)No
*If yes, record spleen size in cm below costal margin.*

At the time of diagnosis: ACU2:CURSIZE **OR** ☐ (ACU2:UNK1) Unknown

At most recent non-acute exam: ACU2:RECSIZE **OR** ☐ (ACU2:UNK2) Unknown

Was subject transfused? ☐ (ACU2:TRANSF)Yes ☐ (ACU2:TRANSF)No

*If no and the Lowest hgb is* ≤ 4.0, please provide an explanation:

ACU2:TRANSP

Did the event result in death?

☐ (ACU2:DEATH)Yes ☐ (ACU2:DEATH)No

Add Diagnosis

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Bacteremia / Sepsis / Meningitis | Bacteremia/Sepsis/Meningitis<br>Page 1 of 1 |
|---|---|---|
| **Protocol # 2**<br>**Collaborative Data Project** | Form Completed by BAC1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had bacteremia/sepsis/meningitis during the report period? BAC1:EPISODE

Date of Event: BAC2:EVENTDA / BAC2:EVENTMO / BAC2:EVENTYR
**DD** **MMM** **YYYY**

Delete Event

Culture positive for bacteria, fungus, or virus from a normally sterile site (not a contaminant)?
☐ (BAC2:POSCUL)Yes ☐ (BAC2:POSCUL)No

☐ (BAC2:BLOODCU) Blood culture: ☐ (BAC2:CULRES1) Positive ☐ (BAC2:CULRES1) Negative Date of culture: BAC2:CULT1DA / BAC2:CULT1MO / BAC2:CULT1YR
**DD** **MMM** **YYYY**

Bacteria: BAC2:ORGBAC1 **or** ☐ (BAC2:BNONE1)None

Fungus: BAC2:ORGFUN1 **or** ☐ (BAC2:FNONE1)None

☐ (BAC2:CSFCUL) CSF culture: ☐ (BAC2:CULRES2) Positive ☐ (BAC2:CULRES2) Negative Date of culture: BAC2:CULT2DA / BAC2:CULT2MO / BAC2:CULT2YR
**DD** **MMM** **YYYY**

Bacteria: BAC2:ORGBAC2 **or** ☐ (BAC2:BNONE2)None

Fungus: BAC2:ORGFUN2 **or** ☐ (BAC2:FNONE2)None

Virus: BAC2:ORGVIR2 **or** ☐ (BAC2:VNONE2)None

Clinical Status:

1. Was the patient admitted to the ICU? ☐ (BAC2:CLINST1) Yes ☐ (BAC2:CLINST1) No
2. Did the event result in death? ☐ (BAC2:CLINST2) Yes ☐ (BAC2:CLINST2) No
3. At time of diagnosis, did the patient have an indwelling vascular access device? ☐ (BAC2:CLINST3) Yes ☐ (BAC2:CLINST3) No

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Seizure | CNS CRF Page 1 of 6 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by SEI1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had a seizure during the report period? SEI1:EPISODE

Date of event: SEI2:EVENTDA / SEI2:EVENTMO / SEI2:EVENTYR
**DD** **MMM** **YYYY**

Delete Event

What were the CNS imaging results?

MRI → ☐ (SEI2:MRI) Normal ☐ (SEI2:MRI) Abnormal ☐ (SEI2:MRI) Not Done
CT → ☐ (SEI2:CT) Normal ☐ (SEI2:CT) Abnormal ☐ (SEI2:CT) Not Done
EEG → ☐ (SEI2:EEG) Normal ☐ (SEI2:EEG) Abnormal ☐ (SEI2:EEG) Not Done

Was the final diagnosis a febrile seizure? ☐ (SEI2:DIAG)Yes ☐ (SEI2:DIAG)No

Was the final diagnosis a clinical diagnosis of a non-febrile seizure by a neurologist? ☐ (SEI2:NEURDIA)Yes ☐ (SEI2:NEURDIA)No

Classification
*(Check all that apply)*

☐ (SEI2:CLASS1) Overt stroke
☐ (SEI2:CLASS2) Silent infarct
☐ (SEI2:CLASS3) Vascular anomaly (aneurysm, AV malformation, or moyamoya)
☐ (SEI2:CLASS4) Idiopathic
☐ (SEI2:CLASS5) Familial
☐ (SEI2:CLASS6) Traumatic
☐ (SEI2:CLASS7) Other, specify:

SEI2:OTHSP

Add Event

Submit Query | Cancel | Print

| Comprehensive Sickle Cell Centers | Stroke - Hemorrhagic | CNS CRF<br>Page 2 of 6 |
|---|---|---|
| **Protocol # 2<br>Collaborative Data Project** | Form Completed by STR1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had a hemorrhagic stroke during the report period? STR1:EPISODE

Date of event: STR2:EVENTDA / STR2:EVENTMO / STR2:EVENTYR
**DD** **MMM** **YYYY**

Delete Event

Was hemorrhage present on CT scan or MRI of the brain? ☐ (STR2:HEMOR) Yes ☐ (STR2:HEMOR) No

If **No** hemorrhage was present on CT scan or MRI of the brain, please provide a comment:

STR2:NOHEMSP

Was there positive (bloody) spinal fluid on LP? ☐ (STR2:POSLP) Yes ☐ (STR2:POSLP) No ☐ (STR2:POSLP) Not Done

Was there a neurosurgical intervention? ☐ (STR2:NEURO) Yes ☐ (STR2:NEURO) No

Did the event result in death? ☐ (STR2:DEATH) Yes ☐ (STR2:DEATH) No

Classification
*(From imaging report: check all that apply)*

- ☐ (STR2:CLASS1) Subdural
- ☐ (STR2:CLASS2) Subarachnoid
- ☐ (STR2:CLASS3) Intracerebral
- ☐ (STR2:CLASS4) Intraventricular
- ☐ (STR2:CLASS5) Vascular anomaly (aneurysm, AV malformation, or moyamoya)

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Stroke - Infarctive | CNS CRF Page 3 of 6 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by STR3:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had an infarctive stroke during the report period? STR3:EPISODE

Date of event: STR4:EVENTDA / STR4:EVENTMO / STR4:EVENTYR
**DD** **MMM** **YYYY**

Delete Event

Was there a neurological defect lasting ≥ 1 hour? ☐ (STR4:DEFECT)Yes ☐ (STR4:DEFECT)No

Which tests demonstrated an infarctive event consistent with clinical symptoms?
*(Check all that apply)*
☐ (STR4:MRI)MRI ☐ (STR4:CT)CT ☐ (STR4:NEITHER)Neither

Which types of angiography were performed?
*(Check all that apply)*
☐ (STR4:MRANG) MR-angiography (MRA) ☐ (STR4:CONVANG) Conventional angiography ☐ (STR4:CTANG) CT-angiography ☐ (STR4:NONE) None

Where was the infarct(s) located?
*(Check all that apply)*
☐ (STR4:INF1) Frontal
☐ (STR4:INF2) Parietal
☐ (STR4:INF3) Watershed
☐ (STR4:INF4) Deep white matter
☐ (STR4:INF5) Other, specify:

STR4:OTHSP

Did the event result in death? ☐ (STR4:DEATH)Yes ☐ (STR4:DEATH)No

Add Event

Submit Query | Cancel | Print

Date of scan: SSCI:EVENTDA / SSCI:EVENTMO / SSCI:EVENTYR

**DD** **MMM** **YYYY**

Delete Event

How many areas of increased T2 signal consistent with infarct/infarction did this subject have?

☐ (SSCI:T2SIG) 1 ☐ (SSCI:T2SIG) 2-5 ☐ (SSCI:T2SIG) 6-10 ☐ (SSCI:T2SIG) >10

Where was the infarct(s) located?

*(Check all that apply)*

- ☐ (SSCI:INF1) Frontal
- ☐ (SSCI:INF2) Parietal
- ☐ (SSCI:INF3) Watershed
- ☐ (SSCI:INF4) Deep white matter
- ☐ (SSCI:INF5) Other, specify:

SSCI:OTHSP

Neurologic Examination was:

- ☐ (SSCI:NEUREXM) Not Done
- ☐ (SSCI:NEUREXM) Normal
- ☐ (SSCI:NEUREXM) Abnormal, consistent with the lesion
- ☐ (SSCI:NEUREXM) Abnormal, not related to the lesion

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Elevated TCD Velocities | CNS CRF<br>Page 5 of 6 |
|---|---|---|
| **Protocol # 2<br>Collaborative Data Project** | Form Completed by TCD1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had a TCD with an elevated velocity* (conditional or abnormal) during the report period? TCD1:EPISODE

* For a non-duplex machine, an elevated velocity is defined as ≥ 170 cm/sec. For a duplex machine, an elevated velocity is defined as ≥ 153 cm/sec.

Date of first elevated velocity: (in this report period) TCD1:ELEVDA / TCD1:ELEVMO / TCD1:ELEVYR
**DD** **MMM** **YYYY**

TCD Ultrasonography values (if range recorded, enter the high end of the range)

| | Left | | Right | |
|---|---|---|---|---|
| MCA: | TCD1:LMCA cm/sec | ☐ (TCD1:LMCANA) Not Available | TCD1:RMCA cm/sec | ☐ (TCD1:RMCANA) Not Available |
| ICA: | TCD1:LICA cm/sec | ☐ (TCD1:LICANA) Not Available | TCD1:RICA cm/sec | ☐ (TCD1:RICANA) Not Available |

Machine: ☐ (TCD1:MACHINE)Duplex ☐ (TCD1:MACHINE)Non-duplex

Were subsequent TCDs done? ☐ (TCD1:TCDYN)Yes ☐ (TCD1:TCDYN)No

If yes, press the "Add" button to record all subsequent TCD examinations performed.

Date of exam: TCD2:EXAMDA / TCD2:EXAMMO / TCD2:EXAMYR Machine: ☐ (TCD2:MACHINE2) Duplex ☐ (TCD2:MACHINE2) Non-duplex Delete Exam
**DD** **MMM** **YYYY**

| | Left | | Right | |
|---|---|---|---|---|
| MCA: | TCD2:LMCA2 cm/sec | ☐ (TCD2:LMCANA2) Not Available | TCD2:RMCA2 cm/sec | ☐ (TCD2:RMCANA2) Not Available |
| ICA: | TCD2:LICA2 cm/sec | ☐ (TCD2:LICANA2) Not Available | TCD2:RICA2 cm/sec | ☐ (TCD2:RICANA2) Not Available |

Add Exam

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Transient Ischemic Attack | CNS CRF Page 6 of 6 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by TIA1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had a transient ischemic attack during the report period? TIA1:EPISODE

Date of event: TIA2:EVENTDA / TIA2:EVENTMO / TIA2:EVENTYR  Delete Event

**DD** **MMM** **YYYY**

Test Results

| | | | |
|---|---|---|---|
| MRA → | ☐ (TIA2:MRA) Normal | ☐ (TIA2:MRA) Abnormal | ☐ (TIA2:MRA) Not Done |
| MRI → | ☐ (TIA2:MRI) Normal | ☐ (TIA2:MRI) Abnormal | ☐ (TIA2:MRI) Not Done |
| CT → | ☐ (TIA2:CT) Normal | ☐ (TIA2:CT) Abnormal | ☐ (TIA2:CT) Not Done |
| EEG → | ☐ (TIA2:EEG) Normal | ☐ (TIA2:EEG) Abnormal | ☐ (TIA2:EEG) Not Done |

Was there clear history of neurological dysfunction resolving within approximately one hour after onset? ☐ (TIA2:RESOLV)Yes ☐ (TIA2:RESOLV)No

Did an examination by a physician document resolution of neurological symptoms? ☐ (TIA2:EXAM)Yes ☐ (TIA2:EXAM)No

Add Event

Submit Query  Cancel  Print

| Comprehensive Sickle Cell Centers | Hepatic Sequestration | GI/Hepatobiliary CRF Page 1 of 3 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by GHP1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had hepatic sequestration during the report period? GHP1:EPISODE

Date of Event: GHP2:EVENTDA / GHP2:EVENTMO / GHP2:EVENTYR
**DD** **MMM** **YYYY**

Delete Event

Baseline Hgb: GHP2:BHGB g/dL  Lowest Hgb: GHP2:LHGB g/dL

Lowest absolute reticulocyte count: GHP2:LARC / $mm^3$
**OR**

Lowest % Retic: GHP2:LRETIC %  Red Cell Count: GHP2:REDC million

Highest direct bilirubin (mg/dL): GHP2:DBILI **or** ☐ (GHP2:DBILIND) Not Done

Was the liver palpable below right costal margin? ☐ (GHP2:PALP)Yes ☐ (GHP2:PALP)No

*If yes, record liver size in cm below costal margin:*

At the time of diagnosis: GHP2:CURRSIZ **or** ☐ (GHP2:UNK1) Unknown

At most recent non-acute exam: GHP2:RECSIZ **or** ☐ (GHP2:UNK2) Unknown

Add Event

Submit Query  Cancel  Print

| Comprehensive Sickle Cell Centers | Intrahepatic Cholestasis | GI/Hepatobiliary CRF Page 2 of 3 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by GHP3:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had intrahepatic cholestasis during the report period? GHP3:EPISODE

Date of Event: GHP4:EVENTDA / GHP4:EVENTMO / GHP4:EVENTYR  Delete Event
**DD** **MMM** **YYYY**

Baseline serum bilirubin Total: GHP4:BSBILI mg/dL Direct: GHP4:BDSBILI mg/dL

Highest serum bilirubin Total: GHP4:HSBILI mg/dL Direct: GHP4:HSDBILI mg/dL

Highest PT result: GHP4:PTVALUE sec **or** ☐ (GHP4:PTND) Not Done

Upper limit of lab normal: GHP4:HPTT

INR: GHP4:INRR

Was an abdominal ultrasound done? ☐ (GHP4:ULDONE)Yes ☐ (GHP4:ULDONE)No

*If yes:*

Was there common bile duct dilation? ☐ (GHP4:BILE) Yes ☐ (GHP4:BILE) No

Were gallstones present? ☐ (GHP4:GALLST) Yes ☐ (GHP4:GALLST) No

Was the liver palpable below mid-right costal margin? ☐ (GHP4:PALP)Yes ☐ (GHP4:PALP)No

*If yes, record liver size in cm below costal margin:*

At the time of diagnosis: GHP4:CURRSIZ **or** ☐ (GHP4:UNK1)Unknown

At most recent non-acute exam: GHP4:RECSIZ **or** ☐ (GHP4:UNK2)Unknown

Did the event result in death? ☐ (GHP4:DEATH)Yes ☐ (GHP4:DEATH)No

Add Event

Submit Query  Cancel  Print

| Comprehensive Sickle Cell Centers | Viral Hepatitis | GI/Hepatobiliary CRF Page 3 of 3 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by VHP1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had viral hepatitis during the report period? VHP1:EPISODE

Date of event: VHP2:EVENTDA / VHP2:EVENTMO / VHP2:EVENTYR  Delete Event
**DD** **MMM** **YYYY**

Max ALT value: VHP2:MAXALT  Upper limit of normal: VHP2:LIMIT

Anti-HAV IgM: ☐ (VHP2:HAV) Positive ☐ (VHP2:HAV) Negative ☐ (VHP2:HAV) Not Done

HBsAg: ☐ (VHP2:HBS) Positive ☐ (VHP2:HBS) Negative ☐ (VHP2:HBS) Not Done

If HBsAg was positive, positive for > 6 months? ☐ (VHP2:POSHBS) Yes ☐ (VHP2:POSHBS) No ☐ (VHP2:POSHBS) Unknown

Anti-HBc IgM: ☐ (VHP2:ANTIHBC) Positive ☐ (VHP2:ANTIHBC) Negative ☐ (VHP2:ANTIHBC) Not Done

HCV: ☐ (VHP2:HCV) Positive ☐ (VHP2:HCV) Negative ☐ (VHP2:HCV) Not Done

HBeAg: ☐ (VHP2:HBEAG) Positive ☐ (VHP2:HBEAG) Negative ☐ (VHP2:HBEAG) Not Done

HB Viral load: VHP2:HB1 IU/mL **or** VHP2:HB2 copies/mL **or** ☐ (VHP2:HBND) Not Done

HC Viral load: VHP2:HC1 IU/mL **or** VHP2:HC2 copies/mL **or** ☐ (VHP2:HCND) Not Done

Liver Biopsy ☐ (VHP2:LIVER)Yes ☐ (VHP2:LIVER)No
If yes, result:

VHP2:BIOPSP

Did the event result in death? ☐ (VHP2:DEATH)Yes ☐ (VHP2:DEATH)No

Add Event

Submit Query  Cancel  Print

| Comprehensive Sickle Cell Centers | Acute Chest Syndrome | Pulmonary CRF Page 1 of 3 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by PUL1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had acute chest syndrome during the report period? PUL1:EPISODE

Date of diagnosis: PUL2:DIAGDA / PUL2:DIAGMO / PUL2:DIAGYR Delete Event
**DD** **MMM** **YYYY**

Was there radiographic evidence of a new segmental or lobar pulmonary infiltrate at the time of diagnosis? ☐ (PUL2:PULQ1) Yes ☐ (PUL2:PULQ1) No ☐ (PUL2:PULQ1) Not Done

Did the subject have tachypnea (per age-adjusted normal values) at the time of diagnosis? ☐ (PUL2:PULQ2) Yes ☐ (PUL2:PULQ2) No ☐ (PUL2:PULQ2) Unknown

Highest temperature at diagnosis: PUL2:TEMP °C

$PaO_2$: PUL2:PAO2 mmHg **or** ☐ (PUL2:PAO2ND) Not Done

$SpO_2$ at the time of diagnosis: PUL2:SPO2DIA %

$O_2$ at the time of $SpO_2$: ☐ (PUL2:ROOM1) Room Air **or** PUL2:OTIME1 % **or** PUL2:LFLOW1 Liter flow

$SpO_2$ at the most recent non-acute exam: PUL2:SPO2EXA %

$O_2$ at the time of $SpO_2$: ☐ (PUL2:ROOM2) Room Air **or** PUL2:OTIME2 % **or** PUL2:LFLOW2 Liter flow

Mark all symptoms reported/experienced by the subject:

☐ (PUL2:SYM1) Cough ☐ (PUL2:SYM2) Chest pain ☐ (PUL2:SYM3) Wheezing ☐ (PUL2:SYM4) Rales
☐ (PUL2:SYM5) Intracostal retractions ☐ (PUL2:SYM6) Nasal flaring ☐ (PUL2:SYM7) Use of accessory muscles for respiration
☐ (PUL2:SYM8) None

Was mechanical ventilation required? ☐ (PUL2:VENTYN)Yes ☐ (PUL2:VENTYN)No

Did the event result in death? ☐ (PUL2:DEATH)Yes ☐ (PUL2:DEATH)No

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Pulmonary Embolism | Pulmonary CRF Page 2 of 3 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by PUL3:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had a pulmonary embolism during the report period? PUL3:EPISODE

Date of event: PUL4:EVENTDA / PUL4:EVENTMO / PUL4:EVENTYR Delete Event
**DD** **MMM** **YYYY**

D-dimer value PUL4:DDIMER ng/mL **or** ☐ (PUL4:DIMERND) Not Done

| | | | |
|---|---|---|---|
| Ventilation/perfusion scan showing 2 or more segmental perfusion defects without corresponding ventilation defects? | ☐ (PUL4:PULQ3) Yes | ☐ (PUL4:PULQ3) No | ☐ (PUL4:PULQ3) Not Done |
| Angiography showing intraluminal filling defects? | ☐ (PUL4:PULQ4) Yes | ☐ (PUL4:PULQ4) No | ☐ (PUL4:PULQ4) Not Done |
| Computed tomography of the pulmonary artery showing intraluminal filling defects? | ☐ (PUL4:PULQ5) Yes | ☐ (PUL4:PULQ5) No | ☐ (PUL4:PULQ5) Not Done |
| In the physician's clinical opinion, did this event represent pulmonary embolism (rather than pulmonary infarction)? | ☐ (PUL4:PULQ6) Yes | ☐ (PUL4:PULQ6) No | |

Bronchoalveolar lavage (BAL)
☐ (PUL4:BALL)Positive for lipid laden macrophages
☐ (PUL4:BALL)Negative
☐ (PUL4:BALL)Not Done

Did the event result in death? ☐ (PUL4:DEATH)Yes ☐ (PUL4:DEATH)No

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Pulmonary Hypertension | Pulmonary CRF Page 3 of 3 |
|---|---|---|
| Protocol # 2 Collaborative Data Project | Form Completed by PUL5:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had a cardiac echo demonstrating pulmonary hypertension during the report period? PUL5:EPISODE

Delete Event

Date of test: PUL6:TESTDA / PUL6:TESTMO / PUL6:TESTYR (dd/mmm/yyyy)

Was this test done during steady state? ☐ (PUL6:TESTYN)Yes ☐ (PUL6:TESTYN)No

Echocardiography tricuspid regurgitant jet velocity: PUL6:ECHORES m/sec **OR** ☐ (PUL6:ECHOND)Not done

Pulmonary Arterial Pressure **OR** ☐ **(PUL6:PAPND)**Not done

Systolic PUL6:BPSYS mmHg

Diastolic PUL6:BPDIA mmHg

Mean PUL6:MEANPAP mmHg

Add Event

Submit Query | Cancel | Print

| Comprehensive Sickle Cell Centers | Acute Renal Failure | Renal/Genitourinary CRF Page 1 of 5 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by REN1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had acute renal failure during the report period? REN1:EPISODE

Date of event: REN2:EVENTDA / REN2:EVENTMO / REN2:EVENTYR
**DD** **MMM** **YYYY**

Delete Event

Baseline creatinine: REN2:BCREAT mg/dL **or** ☐ (REN2:CREATND) Not Done

Highest creatinine: REN2:HCREAT mg/dL

Was dialysis required? ☐ (REN2:DIALYN)Yes ☐ (REN2:DIALYN)No

If yes, start date: REN2:STARTDA / REN2:STARTMO / REN2:STARTYR
**DD** **MMM** **YYYY**

If yes, stop date: REN2:STOPDA / REN2:STOPMO / REN2:STOPYR **or** ☐ (REN2:ONGO) Ongoing
**DD** **MMM** **YYYY**

If yes, type(s): ☐ (REN2:HEMO)Hemodialysis ☐ (REN2:PERI)Peritoneal dialysis
*(check all that apply)*

Was renal or ureteral obstruction present on imaging? ☐ (REN2:RENQ1) Yes ☐ (REN2:RENQ1) No

Does this subject have a history of recurrent urinary tract or kidney infection? ☐ (REN2:RENQ2) Yes ☐ (REN2:RENQ2) No

Does this subject have a history of kidney stones? ☐ (REN2:RENQ3) Yes ☐ (REN2:RENQ3) No

Add Event

Submit Query Cancel Print

What was the highest creatinine recorded in the last 6 months? REN3:HCREAT mg/dL

Date recorded: REN3:HIGHDA / REN3:HIGHMO / REN3:HIGHYR **(dd/mmm/yyyy)**

Date of last creatinine < 1.0 mg/dL: REN3:LASTDA / REN3:LASTMO / REN3:LASTYR **(dd/mmm/yyyy)** **OR** ☐ **(REN3:UNKDT)** Unknown

What was the lowest GFR recorded in the last 6 months? REN3:GFR mL/min/1.73m² **OR** ☐ **(REN3:GFRND)** Not done

Date recorded: REN3:GRFDA / REN3:GRFMO / REN3:GRFYR **(dd/mmm/yyyy)**

Method ☐ (REN3:METHOD) DTPA ☐ (REN3:METHOD) Calculation from Schwartz equation ☐ (REN3:METHOD) GLOFIL ☐ (REN3:METHOD) Other, specify: REN3:OTHSP

Was dialysis initiated during this interval? ☐ (REN3:DIAL1YN) Yes ☐ (REN3:DIAL1YN) No

Was dialysis stopped during this interval? ☐ (REN3:DIAL2YN) Yes ☐ (REN3:DIAL2YN) No

If yes, type(s) ☐ (REN3:HEMO) Hemodialysis ☐ (REN3:PERI) Peritoneal dialysis

*(check all that apply)*

Renal transplant during this interval? ☐ (REN3:TRANYN) Yes ☐ (REN3:TRANYN) No

Did the chronic renal failure result in death during this interval? ☐ (REN3:DEATH) Yes ☐ (REN3:DEATH) No

Submit Query Cancel Print

How many times has this subject had hematuria during the report period? REN4:EPISODE

For the **worst** case of hematuria in any 1 month: Delete Event

Date of event: REN5:EVENTDA / REN5:EVENTMO / REN5:EVENTYR
**DD** **MMM** **YYYY**

Was macroscopic or gross blood seen in the urine? ☐ (REN5:HEMAQ1)Yes ☐ (REN5:HEMAQ1)No

Was the blood present only on a urinalysis or dipstick? ☐ (REN5:HEMAQ2)Yes ☐ (REN5:HEMAQ2)No

Urinalysis results:

Protein:
☐ (REN5:PROTEIN)Negative ☐ (REN5:PROTEIN)Trace ☐ (REN5:PROTEIN)30 mg/dL or 1+ ☐ (REN5:PROTEIN)100 mg/dL or 2+ ☐ (REN5:PROTEIN)300 mg/dL or 3+ ☐ (REN5:PROTEIN)2000 mg/dL or 4+

Blood:
☐ (REN5:BLOOD)Negative ☐ (REN5:BLOOD)Trace ☐ (REN5:BLOOD)Small or 1+ ☐ (REN5:BLOOD) Moderate or 2+ ☐ (REN5:BLOOD)Large or 3+

Nitrite:
☐ (REN5:NITRITE)Negative ☐ (REN5:NITRITE)Positive

Leukocyte Esterase:
☐ (REN5:LEUKEST)Negative ☐ (REN5:LEUKEST)Trace ☐ (REN5:LEUKEST)Small or 1+ ☐ (REN5:LEUKEST)Moderate or 2+ ☐ (REN5:LEUKEST)Large or 3+

WBC: REN5:WBC / HPF RBC: REN5:RBC / HPF

Urine culture results:
☐ (REN5:RESULT)Not Done
☐ (REN5:RESULT)Done and no growth
☐ (REN5:RESULT)Done and positive:
REN5:POSSP

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Priapism | Renal/Genitourinary CRF Page 4 of 5 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by REN6:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many episodes of priapism (days with priapism at least once) has the subject had during the report period? REN6:PRIAP1

How long did the longest episode last (the only episode if only one)? REN6:PRIAP2

Submit Query | Cancel | Print

| Comprehensive Sickle Cell Centers | Proteinuria/Nephrotic Syndrome | Renal/Genitourinary CRF<br>Page 5 of 5 |
|---|---|---|
| **Protocol # 2**<br>**Collaborative Data Project** | Form Completed by REN8:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had proteinuria/nephrotic syndrome during the report period? REN8:EPISODE

For the **worst** case of proteinuria/nephrotic syndrome in any 1 month: Delete Event

Date of event: REN9:EVENTDA / REN9:EVENTMO / REN9:EVENTYR (dd/mmm/yyyy)

Urinalysis results:

Protein:

☐ (REN9:PROT) Negative ☐ (REN9:PROT) Trace ☐ (REN9:PROT) 30 mg/dL or 1+ ☐ (REN9:PROT) 100 mg/dL or 2+ ☐ (REN9:PROT) 300 mg/dL or 3+ ☐ (REN9:PROT) 2000 mg/dL or 4+

Blood (or heme):

☐ (REN9:BLOOD) Negative ☐ (REN9:BLOOD) Trace* ☐ (REN9:BLOOD) Small or 1+ ☐ (REN9:BLOOD) Moderate or 2+ ☐ (REN9:BLOOD) Large or 3+

Nitrite:

☐ (REN9:NITRITE) Negative ☐ (REN9:NITRITE) Positive

Leukocyte Esterase:

☐ (REN9:LEUKO) Negative ☐ (REN9:LEUKO) Trace ☐ (REN9:LEUKO) Small or 1+ ☐ (REN9:LEUKO) Moderate or 2+ ☐ (REN9:LEUKO) Large or 3+

*This includes trace non-hemolyzed, modertate non-hemolyzed, and hemolyzed trace.

WBC: REN9:WBC /HPF RBC: REN9:RBC /HPF

What was the timed urine result (standardize to mg/24 hours)? REN9:TIMERSL

Date recorded: REN9:URECODA / REN9:URECOMO / REN9:URECOYR (dd/mmm/yyyy)

What was the lowest total serum protein recorded? REN9:SERPROT mg/dL

Date recorded: REN9:SRECODA / REN9:SRECOMO / REN9:SRECOYR (dd/mmm/yyyy)

What was the highest creatinine recorded? REN9:CREAT mg/dL

Date recorded: REN9:CRECODA / REN9:CRECOMO / REN9:CRECOYR (dd/mmm/yyyy)

Has dialysis been required? ☐ (REN9:DIALYN) Yes ☐ (REN9:DIALYN) No

*If yes:*

Type(s): ☐ (REN9:HEMO) Hemodialysis ☐ (REN9:PERI) Peritoneal dialysis

Ongoing?: ☐ (REN9:DIAONGO) Yes ☐ (REN9:DIAONGO) No

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Chronic Hypersplenism | Splenic CRF<br>Page 1 of 1 |
|---|---|---|
| **Protocol # 2<br>Collaborative Data Project** | Form Completed by SPLE:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

Distance below the left costal margin (largest over the past 6 months): SPLE:DIST cm

Platelet count:

Baseline: SPLE:BPLAT x $10^3$ cells/$mm^3$

Most recent steady state: SPLE:RPLAT x $10^3$ cells/$mm^3$

Date of steady state test: SPLE:TEST1DA / SPLE:TEST1MO / SPLE:TEST1YR
**DD** **MMM** **YYYY**

Hemoglobin:

Baseline: SPLE:BHGB g/dL

Most recent steady state: SPLE:RHGB g/dL

Date of steady state test: SPLE:TEST2DA / SPLE:TEST2MO / SPLE:TEST2YR
**DD** **MMM** **YYYY**

WBC:

Baseline: SPLE:BWBC x $10^3$ cells/$mm^3$

Most recent steady state: SPLE:RWBC x $10^3$ cells/$mm^3$

Date of steady state test: SPLE:TEST3DA / SPLE:TEST3MO / SPLE:TEST3YR
**DD** **MMM** **YYYY**

Splenectomy? ☐ (SPLE:SPLENEC)Yes ☐ (SPLE:SPLENEC)No

Submit Query | Cancel | Print

| Comprehensive Sickle Cell Centers | Avascular Necrosis | Muscular/Skin/Skeletal Page 1 of 2 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by MUS1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

Location(s):
*(check all that apply)*

☐ (MUS1:HIP) Hip(s) → ☐ (MUS1:RHIP) Right ☐ (MUS1:LHIP) Left

☐ (MUS1:SHLDR) Shoulder(s) → ☐ (MUS1:RSHLDR) Right ☐ (MUS1:LSHLDR) Left

☐ (MUS1:OTHBONE) Other bone(s), specify: MUS1:BONESP

Surgery for condition? ☐ (MUS1:SURG)Yes ☐ (MUS1:SURG)No

*If yes, be sure to complete the Surgical Procedures form!*

If yes, joint replacement? ☐ (MUS1:JOINT)Yes ☐ (MUS1:JOINT)No

Record the following information for all radiographs taken during the report period: ☐ (MUS1:NONE)None taken

| Date of Radiograph | Ficat Stage |
|---|---|
| RADI:RADIDA / RADI:RADIMO / RADI:RADIYR | RADI:FICAT |
| **(DD/MMM/YYYY)** | |

Delete Radiograph

Add Radiograph

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | **Osteomyelitis** (Acute or Chronic) | Muscular/Skin/Skeletal Page 2 of 2 |
|---|---|---|
| **Protocol # 2 Collaborative Data Project** | Form Completed by MUS2:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

How many times has this subject had osteomyelitis during the report period? MUS2:EPISODE

Date of diagnosis: MUS3:DIAGDA / MUS3:DIAGMO / MUS3:DIAGYR
**DD** **MMM** **YYYY**

Delete Diagnosis

Location(s)

List up to two locations: **or** ☐ (MUS3:MFOCAL)Multifocal

Location 1

MUS3:LOCAT1

Location 2

MUS3:LOCAT2

Was a culture done? ☐ (MUS3:CULTYN)Yes ☐ (MUS3:CULTYN)No

**If Yes**, culture site(s): ☐ (MUS3:BLOOD)Blood ☐ (MUS3:BONE)Bone

Organism(s):
*(check all that apply)*

☐ (MUS3:ORG1)*Salmonella* spp. ☐ (MUS3:ORG2)*S. aureus* ☐ (MUS3:ORG3)*H. influenzae*
☐ (MUS3:ORG4)*E. coli* ☐ (MUS3:ORG5)Other, specify:

MUS3:ORGSP

☐ (MUS3:ORG6)No organisms found

If no organisms found, was patient treated presumptively? ☐ (MUS3:ORGYN)Yes ☐ (MUS3:ORGYN)No

Add Diagnosis

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Myocardial Infarction | Cardiac CRF<br>Page 1 of 1 |
|---|---|---|
| **Protocol # 2<br>Collaborative Data Project** | Form Completed by MYO1:COMPINT | CSCC ID: {subject.name}<br>Center Code: {center.name}<br>Hospital Code: {center.hospital.name} |

**NOTE: The investigator must complete this form.**

How many times has this subject had a myocardial infarction during the report period? MYO1:EPISODE

Date of event: MYO2:EVENTDA / MYO2:EVENTMO / MYO2:EVENTYR (dd/mmm/yyyy) Delete Event

☐ (MYO2:ACUEKG) Acute EKG changes consistent with MI (per ACLS Guidelines)

| Time<br>hh:mm | MB-CK<br>IU/L | Troponin I<br>ng/mL | Troponin T<br>ng/mL |
|---|---|---|---|
| Onset Time<br>MYO2:TIME1HR : MYO2:TIME1MI | MYO2:MBCK1 | MYO2:TROPI1 | MYO2:TROPT1 |
| MYO2:TIME2HR : MYO2:TIME2MI | MYO2:MBCK2 | MYO2:TROPI2 | MYO2:TROPT2 |
| MYO2:TIME3HR : MYO2:TIME3MI | MYO2:MBCK3 | MYO2:TROPI3 | MYO2:TROPT3 |
| MYO2:TIME4HR : MYO2:TIME4MI | MYO2:MBCK4 | MYO2:TROPI4 | MYO2:TROPT4 |
| MYO2:TIME5HR : MYO2:TIME5MI | MYO2:MBCK5 | MYO2:TROPI5 | MYO2:TROPT5 |

Did the event result in death? ☐ (MYO2:DEATH) Yes ☐ (MYO2:DEATH) No

Was an autopsy performed? ☐ (MYO2:AUTOPSY) Yes ☐ (MYO2:AUTOPSY) No

**If Yes,** myocardial infarction was demonstrated by:

☐ (MYO2:HRTEXAM) Gross examination of the heart at autopsy

☐ (MYO2:HISTSTN) Standard hisological stain

☐ (MYO2:NITRSTN) Nitro blue tetrazolium stain

☐ (MYO2:HFPASTN) Hematoxylin-fuchsin-picric acid stain

Add Event

Submit Query Cancel Print

| Comprehensive Sickle Cell Centers | Annual Form Part IIA<br>Patient Interview | Page: {section.pageNumber} |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: AF2A:COMPDA (DD) / AF2A:COMPMO (MMM) / AF2A:COMPYR (YYYY)<br>Form Completed by: AF2A:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

Was this interview conducted in person or by phone? ☐ (AF2A:INTVW) In person ☐ (AF2A:INTVW) By phone

1a. **How many siblings do you have?** AF2A:SIBLNO

**Of the siblings who share both your biological mother and father:**

1b. How many have SCD? AF2A:SIBWSCD

1c. How many do not have SCD? AF2A:SIBNSCD

2. **What is your current employment status?** Are you: ☐ (AF2A:EMPLOY) Full Time, ☐ (AF2A:EMPLOY) Part Time, or ☐ (AF2A:EMPLOY) Not Employed

3. **What is your current student status?** Are you: ☐ (AF2A:STUSTAT) Full Time, ☐ (AF2A:STUSTAT) Part Time, or ☐ (AF2A:STUSTAT) Not a Student

4. **What is the highest grade of school you have completed, or how many years of college have you completed?** AF2A:HIGHGRD *(Enter 0 for pre-school or less, K for kindergarten, 1-12, 13 = 1 year college, 14 = 2 years college, etc.)*

5. **What is the number of individuals (19 years of age and up) in your household?** AF2A:INDGT19

6. **What is the number of individuals (under 19 years of age) in your household?** AF2A:INDLT19

7. **What type of health insurance do you have?** *(check all that apply)*

☐ (AF2A:PRIVATE) Private ☐ (AF2A:MEDCARE) Medicare ☐ (AF2A:MEDCAID) Medicaid ☐ (AF2A:NONEINS) None ☐ (AF2A:OTHINS) Other AF2A:HLTHSP

8a. **In the past year, have you received sickle cell-related healthcare from any other center or institution?**

☐ (AF2A:SCHLTH) Yes ☐ (AF2A:SCHLTH) No ☐ (AF2A:SCHLTH) Unknown

. *8b. [If yes]* **Where?** **How many times?**

AF2A:SCWHER1 AF2A:SCTIME1

AF2A:SCWHER2 AF2A:SCTIME2

AF2A:SCWHER3 AF2A:SCTIME3

9a. **In the past year, have you ever had a headache?**

☐ (AF2A:HEADACH) Yes ☐ (AF2A:HEADACH) No ☐ (AF2A:HEADACH) Unknown

*9b. [If yes]* How many headaches have you had? AF2A:HEAD1

9c. How many of these headaches occurred while you had sickle pain? AF2A:HEAD2 *Put 0 for none*

. 9d. How many of these headaches were not associated with sickle pain, fever/illness or alcohol? AF2A:HEAD3 *Put 0 for none*

10a. **Have you received a transfusion in the past year?** ☐ (AF2A:TRANPY) Yes ☐ (AF2A:TRANPY) No ☐ (AF2A:TRANPY) Unknown

*10b. [If yes]* How many transfusions? ☐ (AF2A:TRANNO) 1-5 ☐ (AF2A:TRANNO) 6-20 ☐ (AF2A:TRANNO) 21-99 ☐ (AF2A:TRANNO) 100+

11. **In the past year, how many days of work or school have you missed due to your Sickle Cell Disease?** AF2A:DAYMISS *Put 0 for none*

12. **In the past year, how many times have you come to the doctor's office, the day hospital, Emergency Department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease?** AF2A:SCPAINY *Put 0 for none*

13. **In the past year, what was the total number of painful episodes due to Sickle Cell Disease for which you were treated solely at home?** AF2A:EPISNO *Put 0 for none*

**For Female Patients:** ☐ (AF2A:FPATNA) NA (for males and females not of child-bearing potential)

14. **Are you currently pregnant?** ☐ (AF2A:CURPREG) Yes ☐ (AF2A:CURPREG) No ☐ (AF2A:CURPREG) Unknown

15a. **Have you been pregnant within the past year (exclude current pregnancy if applicable)?** ☐ (AF2A:PREGPY) Yes ☐ (AF2A:PREGPY) No ☐ (AF2A:PREGPY) Unknown

How many previous pregnancies have resulted in: *(number):*

15b. AF2A:FULLB Full term births 15c. AF2A:MISSCAR Miscarriages (spontaneous abortions) 15d. AF2A:LIVEB Live births

15e. AF2A:PREMB Premature births 15f. AF2A:ABORT Abortions (elective) 15g. AF2A:MULTB Multiple births

15h. AF2A:LIVEC Live children at present

*[If 15g is a number other than '0']* Record the type of multiple birth for each (i.e., "twins"):

Multiple birth 1: AF2A:MULTB1

Multiple birth 2: AF2A:MULTB2

Multiple birth 3: AF2A:MULTB3

PI/SC Signature: ☐ (AF2A:PICHECK) Date: AF2A:SIGNDA / AF2A:SIGNMO / AF2A:SIGNYR

DD MMM YYYY

Submit Query Cancel Form Completion Help Print

| Comprehensive Sickle Cell Centers | Annual Form Part IIA Patient Interview | Page: 3 |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: {COMPDT}<br>Form Completed by: {COMPINT} | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Tobacco Use in the past year**

| | | | | |
|---|---|---|---|---|
| 16. | **Did you use any type of tobacco in the past year?** | ☐ (TO2A:ANYTOB) Yes | ☐ (TO2A:ANYTOB) No | ☐ (TO2A:ANYTOB) Unknown |
| 17a. | **Do you currently use tobacco?** | ☐ (TO2A:CURTOB) Yes | ☐ (TO2A:CURTOB) No | ☐ (TO2A:CURTOB) Unknown |

| | | | | |
|---|---|---|---|---|
| *[If yes]* | 17b. What is your usual number of **cigarettes?** | TO2A:CIGET | per | TO2A:CIGETFR |
| | 17c. What is your usual number of **cigars?** | TO2A:CIGAR | per | TO2A:CIGARFR |
| | 17d. How often do you use **snuff/chew?** | TO2A:SNUF | per | TO2A:SNUFFR |
| | 17e. How often do you smoke a **pipe?** | TO2A:PIPE | per | TO2A:PIPEFR |

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | Annual Form Part IIA Patient Interview | Page: 4 |
|---|---|---|
| Collaborative Data Project | Date of Interview: {COMPDT}<br>Form Completed by: {COMPINT} | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Alcohol Use in the past year**

18. **Did you drink any type of alcohol during the past year?** ☐ (AL2A:ANYALCO) Yes ☐ (AL2A:ANYALCO) No ☐ (AL2A:ANYALCO) Unknown

19a. **Do you currently drink alcohol?** ☐ (AL2A:CURALCO) Yes ☐ (AL2A:CURALCO) No ☐ (AL2A:CURALCO) Unknown

*[If yes]* 19b. What is your usual number of **beers?** AL2A:BEER per AL2A:BEERFR

19c. What is your usual number of **glasses of wine ?** AL2A:WINE per AL2A:WINEFR

19d. What is your usual number of **other alcoholic drinks ?** AL2A:DRINK per AL2A:DRINKFR

Submit Query | Cancel | Form Completion Help | Print

20. **Which of these letters best describes your household's yearly income *during the past year*? This includes the total amount of money for all members of your household combined, from all sources including jobs, disability payments or money from the government?**

| | | | | | |
|---|---|---|---|---|---|
| ☐ (IN2A:INCOMEQ) | A. Under $4,999 | ☐ (IN2A:INCOMEQ) | D. $15,000 - 24,999 | ☐ (IN2A:INCOMEQ) | G. $45,000 and over |
| ☐ (IN2A:INCOMEQ) | B. $5,000 - 9,999 | ☐ (IN2A:INCOMEQ) | E. $25,000 - 34,999 | ☐ (IN2A:INCOMEQ) | H. Prefer not to answer |
| ☐ (IN2A:INCOMEQ) | C. $10,000 - 14,999 | ☐ (IN2A:INCOMEQ) | F. $35,000 - 44,999 | ☐ (IN2A:INCOMEQ) | I. Don't know |

Comments for interview pages 1-4:

IN2A:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Annual Form Part IIB**<br>**Parent (or Accompanying Adult) Interview** | **Page: {section.pageNumber}** |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: AF2B:COMPDA (DD) / AF2B:COMPMO (MMM) / AF2B:COMPYR (YYYY)<br>Form Completed by: AF2B:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

Who is accompanying this child today? ☐ (AF2B:ACCOMP) Parent ☐ (AF2B:ACCOMP) Guardian ☐ (AF2B:ACCOMP) Other adult relative

Was this interview conducted in person or by phone? ☐ (AF2B:INTVW) In person ☐ (AF2B:INTVW) By phone

1a. **How many siblings does this child have?** AF2B:SIBLNO

**Of the siblings who share both this child's biological mother and father:**

1b. How many have SCD? AF2B:SIBWSCD

1c. How many do not have SCD? AF2B:SIBNSCD

2. **What is the highest grade of school this child has completed?** AF2B:HIGHGRD *(Enter 0 for pre-school or less, K for kindergarten, 1-12, 13 = 1 year college, 14 = 2 years college, etc.)*

3. **What is the number of individuals (19 years of age and up) in this child's household?** AF2B:INDGT19

4. **What is the number of individuals (under 19 years of age) in this child's household?** AF2B:INDLT19

5. **What type of health insurance does this child have?** *(check all that apply)*

☐ (AF2B:PRIVATE) Private ☐ (AF2B:MEDCARE) Medicare ☐ (AF2B:MEDCAID) Medicaid ☐ (AF2B:NONEINS) None ☐ (AF2B:OTHINS) Other AF2B:HLTHSP

6a. **In the past year, has this child received sickle cell-related healthcare from any other center or institution?**

☐ (AF2B:SCHLTH) Yes ☐ (AF2B:SCHLTH) No ☐ (AF2B:SCHLTH) Unknown

. *6b. [If yes]* **Where?** **How many times?**

AF2B:SCWHER1 AF2B:SCTIME1

AF2B:SCWHER2 AF2B:SCTIME2

AF2B:SCWHER3 AF2B:SCTIME3

7a. **Has this child been transfused in the past year?** ☐ (AF2B:TRANPY) Yes ☐ (AF2B:TRANPY) No ☐ (AF2B:TRANPY) Unknown

*7b. [If yes]* How many transfusions? ☐ (AF2B:TRANNO) 1-5 ☐ (AF2B:TRANNO) 6-20 ☐ (AF2B:TRANNO) 21-99 ☐ (AF2B:TRANNO) 100+

8a. **In the past year, has your child ever had a headache?** ☐ (AF2B:HEADACH) Yes ☐ (AF2B:HEADACH) No ☐ (AF2B:HEADACH) Unknown

*8b. [If yes,]* How many headaches has he/she had? AF2B:HEAD1

8c. How many of these headaches occurred while he/she had sickle pain? AF2B:HEAD2 *Put 0 for none*

. 8d. How many of these headaches were not associated with sickle pain, fever/illness or alcohol? AF2B:HEAD3 *Put 0 for none*

9. **In the past year, how many days of school has this child missed due to his/her Sickle Cell Disease?** AF2B:CDAYMIS *Put 0 for none*

10. **In the past year, how many days of school or work have the primary caregiver(s) of this child missed due to this child's Sickle Cell Disease?** AF2B:PDAYMIS *Put 0 for none*

11. **In the past year, how many times has this child come to the doctor's office, the day hospital, Emergency Department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease?** AF2B:PAINVIS *Put 0 for none*

12. **In the past year, what was the total number of painful episodes due to Sickle Cell Disease for which this child was treated solely at home?** AF2B:PAINNO *Put 0 for none*

PI/SC Signature: ☐ (AF2B:PICHECK) Date: AF2B:SIGNDA / AF2B:SIGNMO / AF2B:SIGNYR

DD MMM YYYY

Submit Query Cancel Form Completion Help Print

| Comprehensive Sickle Cell Centers | Annual Form Part IIB Parent (or Accompanying Adult) Interview | Page: 2 |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: {COMPDT}<br>Form Completed by: {COMPINT} | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

13. **Which of these letters best describes this child's household yearly income *during the past year*? This includes the total amount of money for all members of your household combined, from all sources including jobs, disability payments or money from the government?**

| | | | | | |
|---|---|---|---|---|---|
| ☐ (IN2B:INCOMEQ) | A. Under $4,999 | ☐ (IN2B:INCOMEQ) | D. $15,000 - 24,999 | ☐ (IN2B:INCOMEQ) | G. $45,000 and over |
| ☐ (IN2B:INCOMEQ) | B. $5,000 - 9,999 | ☐ (IN2B:INCOMEQ) | E. $25,000 - 34,999 | ☐ (IN2B:INCOMEQ) | H. Prefer not to answer |
| ☐ (IN2B:INCOMEQ) | C. $10,000 - 14,999 | ☐ (IN2B:INCOMEQ) | F. $35,000 - 44,999 | ☐ (IN2B:INCOMEQ) | I. Don't know |

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Annual Form Part IIB Parent (or Accompanying Adult) Interview** | **Page: 3** |
|---|---|---|
| **Collaborative Data Project** | Date of Interview: {COMPDT}<br>Form Completed by: {COMPINT} | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**For the interviewer:**

14. **Who answered the questions on pages 1 and 2?**

- ☐ (IV2B:INTVWRQ) Primarily the patient
- ☐ (IV2B:INTVWRQ) Primarily the parent/accompanying adult
- ☐ (IV2B:INTVWRQ) Patient and parent/accompanying adult together

Comments for interview pages 1-3:

IV2B:COMTXT

Submit Query | Cancel | Form Completion Help | Print

| Comprehensive Sickle Cell Centers | **Termination/Transfer Form** | |
|---|---|---|
| **Collaborative Data Project** | Date Form Completed: TERM:COMPDA (DD) / TERM:COMPMO (MMM) / TERM:COMPYR (YYYY)<br>Form Completed by: TERM:COMPINT | CSCC ID: {subject.name}<br>Center code: {center.name}<br>Hospital code: {center.hospital.name} |

**Patient is:** ☐ (TERM:PASTAT) Deceased ☐ (TERM:PASTAT) Transferred ☐ (TERM:PASTAT) Lost to follow-up ☐ (TERM:PASTAT) Withdrawn

**Date of death, transfer, withdrawal or date patient determined to be lost to follow-up:** TERM:TRANDA / TERM:TRANMO / TERM:TRANYR (DD/MMM/YYYY)

**If transferred, institution/site transferred to:** TERM:INSTIT

**If patient is deceased:**

Did patient die in hospital? ☐ (TERM:DIEHOSP) Yes ☐ (TERM:DIEHOSP) No ☐ (TERM:DIEHOSP) Unknown

**If yes, be sure to file a copy of the discharge summary with the patient's record and fax a copy to SDMC.**

Was an autopsy performed? ☐ (TERM:AUTOPSY) Yes ☐ (TERM:AUTOPSY) No ☐ (TERM:AUTOPSY) Unknown

*If yes, institution where autopsy was performed:* TERM:AUTOPIN

**If yes, be sure to file a copy of the autopsy report with the patient's record and fax a copy to SDMC or check the box to the right to indicate that the autopsy report is not available.**

☐ (TERM:AUTOPNA) Autopsy report not available

What was the primary cause of death? *(Choose only ONE.)*

☐ (TERM:PRIMARY) Cardiac arrest

☐ (TERM:PRIMARY) CNS event / Stroke / Intracranial hemorrhage

☐ (TERM:PRIMARY) Hepatic failure

☐ (TERM:PRIMARY) Malignancy

☐ (TERM:PRIMARY) Respiratory failure / Pneumonia / Acute chest syndrome

☐ (TERM:PRIMARY) Sepsis / Infection

☐ (TERM:PRIMARY) Severe anemia

☐ (TERM:PRIMARY) Splenic sequestration

☐ (TERM:PRIMARY) Multi-system organ failure

☐ (TERM:PRIMARY) Renal failure

☐ (TERM:PRIMARY) Other, specify: TERM:PRIMSP

☐ (TERM:PRIMARY) Cause of death is unknown

Were there secondary causes of death? ☐ (TERM:SECDCAU)Yes ☐ (TERM:SECDCAU)No

If yes, what was/were the secondary cause(s) of death? *(Check all that apply below.)*

☐ (TERM:SCAR) Cardiac arrest

☐ (TERM:SCNS) CNS event / Stroke / Intracranial hemorrhage

☐ (TERM:SHEPF) Hepatic failure

☐ (TERM:SMALIG) Malignancy

☐ (TERM:SSYSFL) Multi-system organ failure

☐ (TERM:SRENAL) Renal failure

☐ (TERM:SRESP) Respiratory failure / Pneumonia / Acute chest syndrome

☐ (TERM:SSEPSIS) Sepsis / Infection

☐ (TERM:SANEM) Severe anemia

☐ (TERM:SSPLEN) Splenic sequestration

☐ (TERM:SOTHR) Other, specify: TERM:SECDSP

Comments for page:

TERM:COMTXT

Submit Query | Cancel | Form Completion Help | Print