Comprehensive Sickle Cell Centers	**Medical History**	CSCC ID: _____ Site: _____
Epidemiology Priapism DEMO	Date Form Completed: COMPDA / COMPMO / COMPYR (Day / Month / Year) COMPDT	Identifier acrostic: _____ *(for internal use only)* Form completed by: _____ COMPLT

1. Patient's Date of Birth: DOBDA / DOBMO / DOBYR (Day / Month / Year) DOBDT

2. Diagnosis: DIAGNOS ☐ SS ☐ SC ☐ Sβ⁺thal ☐ Sβ⁰thal

3. Is this subject enrolled in C-Data (the CSCC collaborative database)? CENSUS ☐ Yes ☐ No *(If yes, skip Questions 4-6 and continue with Question 7.)*

4. Date first seen in this center: ___ / ___ (Month / Year) VISITMO VISITYR **or** ☐ Unknown FIRSTUK

5. Do you think that the medical history on this case report form is incomplete due to admissions at other hospitals that are not associated with your Center? ☐ Yes ☐ No ☐ Unknown HOSPOTH

If yes, # years at other hospital(s)? HOSPYR _____ List hospital(s), if known: HOSPNME _____

6. From clinical records please indicate if, in his **entire** lifetime, this patient ever had or has been diagnosed with:

Splenic sequestratior	SPLSQ	☐ Yes	☐ No	☐ Unknown	**If known,** year of 1st Dx:	SPLSQYR
Splenectomy?	SPTMY	☐ Yes	☐ No	☐ Unknown	**If known,** year of 1st Dx:	SPTMYYR
Dactylitis?	DACTL	☐ Yes	☐ No	☐ Unknown	**If known,** year of 1st Dx:	DACTLYR
Leg ulcers?	ULCER	☐ Yes	☐ No	☐ Unknown	**If known,** year of 1st Dx:	ULCERYR
Stroke?	AVASC	☐ Yes	☐ No	☐ Unknown	**If known,** year of 1st Dx:	STRKEYR
Acute renal failure?	STRKE	☐ Yes	☐ No	☐ Unknown	**If known,** year of 1st Dx:	ACUTEYR
Avascular necrosis?	ACUTE	☐ Yes	☐ No	☐ Unknown		

If yes, list bone(s) involved and year(s) of first diagnosis (if known):

Bone: BONE1 _____ year of 1st Dx: BONE1YR

Bone: BONE2 _____ year of 1st Dx: BONE2YR

Bone: BONE3 _____ year of 1st Dx: BONE3YR

7. From clinical records please indicate if, in his **entire** lifetime, this patient ever had or has been diagnosed with:

Pulmonary hypertension? ☐ Yes ☐ No ☐ Unknown PULMHYP

If yes, list all known tests performed for diagnosis, procedures performed in relation to this condition, and year(s) of occurrence: PULMTST _____

Sickle cell retinopathy? ☐ Yes ☐ No ☐ Unknown SCELRET

If yes, list all known tests performed for diagnosis, procedures performed in relation to this condition, and year(s) of occurrence: SCELTST _____

Chronic renal failure	CHRNC	☐ Yes	☐ No	☐ Unknown	**If yes,** dialysis? ☐ Yes ☐ N	DIALSIS
Admission for painfu	PNCRS	☐ Yes	☐ No	☐ Unknown	**If yes,** # times: ☐ <10 ☐	NUMPCRS
Acute chest syndror	CHEST	☐ Yes	☐ No	☐ Unknown	**If yes,** # episodes: ___ In the las	ACSLST3
					___ 3 or more	ACS3AGO

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8. Most recent **steady state** lab results and date tests performed:

Hemoglobin: HMGLBN g/dL — HGBDA / HGBMO / HGBYR HGBDT (day / month / year)

Platelet count: PLTLET x10^9 /L — PLTDA / PLTMO / PLTYR PLTDT (day / month / year)

WBC: WBC x10^9 /L — WBCDA / WBCMO / WBCYR WBCDT (day / month / year)

Room air O_2 Sat: O2SAT % **OR** ☐ Not done/ Data not available O2SATND — O2SATDA / O2SATMO / O2SATYR O2SATDT (day / month / year)

Method used for determination: ☐ Pulse oximeter ☐ Other, specify: O2METHS O2METH

9. Has the patient ever been placed on chronic transfusion therapy (planned transfusion about once per month for 3 months or more)? ☐ Yes ☐ No ☐ Unknown CTRAN

9a. If yes, what happened to the frequency of priapism during chronic transfusion therapy? CTRANYS

☐ Increased ☐ Decreased ☐ Stayed about the same ☐ Don't know ☐ Patient was not having episodes of priapism when chronic transfusion was started

10. Has this patient ever taken Hydroxyurea? HYDRX ☐ Yes ☐ No ☐ Unknown

10a. If yes, what happened to the frequency of priapism during Hydroxyurea therapy? HYDRXYS

☐ Increased ☐ Decreased ☐ Stayed about the same ☐ Don't know ☐ Patient was not having episodes of priapism when Hydroxyurea was started

11. Was your clinical program aware, by a mention in the medical record, that this patient had ever had priapism before this questionnaire was conducted? AWARE ☐ Yes ☐ No

11a. If yes, how has it been managed or treated? ***(check all that apply)***

NARCTC ☐ Narcotics and hydration for episodes

TRNSFSN ☐ Transfusion (simple or chronic)

ASPIRRG ☐ Aspiration and irrigation for prolonged episodes

PSEUDO ☐ Pseudoephedrine for prevention

SHUNTS ☐ Surgical shunts (like a Winter or Glenn shunt)

OTHTX ☐ Other, specify: OTHTXSP

NOTREAT ☐ No specific treatment

12. Are there any other issues that you would like to make us aware of relevant to this patient and his problem with priapism, if a problem exists?

ISSUES

NOSHOW

☐ Check this box if the patient did not present for the survey after signing informed consent.