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| Comprehensive Sickle Cell Centers | Survey Instrument Age 5-14 | CSCC ID: <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> |
| Epidemiology MINR Priapism | Interview Date: INTDA <input style="width:20px; height:20px;" type="text"/> / INTMO <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> / INTYR <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> INTDT Day Month Year | Identifier acoustic: _____ (for internal use only) INTINIT Interviewer's initials: <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> <input style="width:20px; height:20px;" type="text"/> |

- Interview male patients between 5 and 14 years of age, inclusive. Parent or guardian may be present if patient desires. Ensure that there is privacy during conversation. Ask the questions as they are written and record responses on this form. Where instructed, read the possible responses to the patient.
- Text in italics is information for the interviewer and should not be read to the patient/parent/guardian.
- Reminder: As the DSMB has instructed, the patient or parent should be given the honorarium regardless of whether they answer any questions.
- Mark the open circle to the left of the question number if the patient declines to answer that question.

Date informed consent signed: INFCDA / INFCMO / INFCYR
INFCDT Day Month Year

NOANSWER Check this box if the patient chose not to attempt the survey after signing informed consent.

Read the following statement to the patient/parent/guardian before beginning the interview: You are free to refuse to answer any questions you do not wish to answer, and you can stop the interview at any time.

Q1NA
 1. Had you ever heard the word "priapism" before today? PRIAP Yes No Not sure

Read the following statement: Priapism is a painful unwanted erection of the penis that lasts 30 minutes or more.

Q2NA
 2. Before today, had you ever heard of this condition happening in sickle cell disease? Yes No Not sure

Q3NA
 3. Have you [Has your son] ever had a painful unwanted erection of the penis that B4TODAY PAIN Yes No Not sure
 lasted 30 minutes or more?

**If answer to #3 is 'No', ask Question 4 and then skip to Question 20.
 If answer to #3 is 'Yes' or 'Not sure', the entire questionnaire should be attempted.**

Q4NA
 4. Before this study, had a doctor or nurse ever talked with you [you or your son] INFO Yes No Not sure
 about priapism OR provided written information?

Q5ANA
 5a. How many episodes of priapism have you [has your son] had in the past year? EPPSTYR
 None 1 2 to 5 6 to 20 More than 20 Don't know

Q5BNA
 5b. How many episodes of priapism did you [your son] have before the past year? EPPRIOR
 None 1 2 to 5 6 to 20 More than 20 Don't know

**If the patient has only had one episode of priapism (Questions 5a+5b=1), ask Question 6 but skip Questions 7 and 8.
 If the patient has had more than one episode of priapism (Questions 5a+5b>1), skip Question 6 and ask Questions 7 and 8.**

6a. How old were you [was your son] when the episode of priapism YMOONLY Years ago
Q6ANA happened or how long ago did the episode happen? AGEONLY Years old **or** AGOONLY Months ago

6b. About how many minutes or hours DURMIN Minutes DURHRS Hours DURDAY Days **or** DURUNK Don't know
Q6BNA did the episode of priapism last?

7a. How old were you [was your son] when the **first episode** of YMOFRST Years ago
Q7ANA priapism happened or how long ago did the first episode happen? AGEFRST Years old **or** AGOFRST Months ago

7b. How old were you [was your son] when the **last episode** of YMOLAST Years ago
Q7BNA priapism happened or how long ago did the last episode happen? AGELAST Years old **or** AGOLAST Months ago

8a. About how many minutes or hours does AVGMIN Minutes AVGHRS Hours AVGDAY Days **or** AVGUNK Don't know
Q8ANA an average episode of priapism last? Q8BNA

8b. What about: The shortest episode? SHRTMIN Minutes SHRTHRS Hours SHRTDAY Days **or** SHRTUNK Don't know
Q8CNA

8c. The longest episode? LONGMIN Minutes LONGHRS Hours LONGDAY Days **or** LONGUNK Don't know

8d. The last episode? LASTMIN Minutes LASTHRS Hours LASTDAY Days **or** LASTUNK Don't know
Q8DNA

Epidemiology Priapism

Identifier acoustic: _____
(for internal use only)

Q9A 9a. What time of the day or night does the priapism most often start? *(Read the responses. Check only one.)* **START**

Midnight to 4 in the morning 4 in the morning to 8 in the morning 8 in the morning to 4 in the afternoon 4 in the afternoon to midnight

Q9BNA 9b. Does priapism most often start when you are [your son is] awake or asleep? *(Question 9c varies with response to this question.)*

| | |
|--|---|
| <input type="checkbox"/> Awake AWKASLP | <input type="checkbox"/> Asleep / Wake up with |
| Q9CNA 9c. How many hours after waking up does it usually begin? <i>(read the responses)</i> AWAKE | How many hours after going to sleep does it usually begin? <i>(read the responses)</i> ASLEEP |
| <input type="checkbox"/> 0-2 hours after waking up | <input type="checkbox"/> 0-4 hours after going to sleep |
| <input type="checkbox"/> 2-12 hours after waking up | <input type="checkbox"/> 4-8 hours after going to sleep |
| <input type="checkbox"/> > 12 hours after waking up | <input type="checkbox"/> 8-12 hours after going to sleep |
| | <input type="checkbox"/> > 12 hours after going to sleep |

Q10NA 10. I am going to read you a list of things that may cause priapism. Do you think that any of these things have caused your [your son's] priapism? *(Read the responses. Check all that apply.)*

- SLEEP** Sleeping **CONSTIP** Constipation **BREATHE** Trouble breathing **SEXACT** Sexual activity (masturbation, intercourse) **SEXTHTS** Sexual thoughts
- ALCOHOL** Alcohol use **MEDS** Medication or drug use (marijuana, herbals, cocaine, antipsychotics) *Specify drug if known:* **MEDSSP** _____
- CAUSOT** Other cause, *specify:* **CAUSOTS** _____ None Don't know

Q11NA 11. Which of the following, if any, do you do to treat the priapism at home? *(Read the responses. Check all that apply.)*

IBUPRO Take non-narcotic pain medication (ibuprofen, acetaminophen, naprosyn) **CODEINE** Take opioids (codeine, hydrocodone) **MEDOT** Other medication, *specify:* **MEDOTS** _____

URINATE Pee/pass urine/urinate **SHOWER** Take a shower or bath **REST** Rest and relax Mild exercise / Get up and walk around

FLUIDS Increase fluids **TXOTH** Other treatment, *specify:* **TXOTHS** _____ **NOHOMET** None

Q12NA 12. Have you [Has your son] ever been seen at the emergency room, been admitted to the hospital, or seen a doctor **during** an episode of priapism? **DURING** Yes No Do not remember

If yes, ask Questions 13 and 14. If 'No' or 'Do not remember' skip to Question 15.

Q13NA 13. I am going to read you a list of treatments. Tell me which ones you remember being given when you were in the emergency room, hospital, or doctor's office while the painful erection or priapism was still going on. *(Read all responses in the "Treatment" column and check all that apply. For each treatment checked, ask Question 13a and record the response of the priapism.)*

If any treatments are checked, ask Question 13a.

Treatment

- ORALMED** Pain medication by mouth **ORALSP** →
- IVFLUID** Intravenous or IV fluid **FLUIDSP** →
- IVMED** Pain medication by vein or shot (IV or IM) **IVMEDSP** →
- TRAN** Red blood cell transfusion **TRANSP** →
- NOTREAT** None / Does not remember any treatments to end the priapism

Q13ANA 13a. When you were given the _____ [treatment], what happened to the priapism? *(read responses)*

| | | |
|---|---|------------------------------------|
| <input type="checkbox"/> Erection went away/ Pain decreased | <input type="checkbox"/> Stayed about the same/ Do not remember | <input type="checkbox"/> Got worse |
| <input type="checkbox"/> Erection went away/ Pain decreased | <input type="checkbox"/> Stayed about the same/ Do not remember | <input type="checkbox"/> Got worse |
| <input type="checkbox"/> Erection went away/ Pain decreased | <input type="checkbox"/> Stayed about the same/ Do not remember | <input type="checkbox"/> Got worse |
| <input type="checkbox"/> Erection went away/ Pain decreased | <input type="checkbox"/> Stayed about the same/ Do not remember | <input type="checkbox"/> Got worse |

Q14NA

14. Do you remember having any of the following surgical procedures to end an episode of priapism either in the emergency department or operating room? (*Read all responses in the "Procedure" column and check all that apply. For each procedure checked, ask Question 14a and record the response of the priapism to the procedure.*)

If any procedures are checked, ask Question 14a.

Procedure

ASPIR

Aspiration, irrigation, or injection
(needle in side of penis to inject medicine or remove blood - may be done in ER or OR)

ASPIRSP

SHUNT

Surgical procedure or shunt
(only done in OR)

SHUNTSP

NOPROC

None / Does not remember any procedures to end the priapism

Q14ANA

14a. When you had the _____ [procedure], what happened to the priapism? (*read the responses*)

Erection went away/
Pain decreased

Stayed about the same/
Do not remember

Got worse

Erection went away/
Pain decreased

Stayed about the same/
Do not remember

Got worse

Q15NA

15. Have you [Has your son] ever received chronic transfusion therapy for any reason (planned red cell transfusion once a month for three months or more)? Yes No Do not remember

CTRAN

Q15ANA

15a. *If yes*, what happened to your [your son's] priapism during this period of chronic transfusion? (*read the responses*)

CTRANYS

Increased

Decreased

Stayed about the same

Was not having episodes of priapism when chronic transfusion was started

Don't know

Q16NA

16. Have you [Has your son] ever received Hydroxyurea therapy? Yes No Don't know

HYDRX

Q16ANA

16a. *If yes*, what happened to your [your son's] priapism during the Hydroxyurea therapy? (*read the responses*)

HYDRXYS

Increased

Decreased

Stayed about the same

Was not having episodes of priapism when Hydroxyurea was started

Don't know

17. The next questions are about regular erections, not priapism or painful erections.

a. Do you [Does your son] get erections? **ERECTNS**

Yes

No

Don't know

b. Do you [Does your son] get erections during the night or wake up with erections? **OVRNITE**

Yes

No

Don't know

Q18NA

18. How does the priapism compare to other problems from your [your son's] sickle cell disease? (*read the responses*) **PROBLEM**

The worst problem

About the same as everything else

Not as bad as other problems

If it is the worst problem, skip to Question 19.

Q18ANA

WORST

18a. Was there ever a time that priapism was the worst problem you [your son] had with sickle cell disease?

Yes

No

Do not remember

Q19NA

19. Is there anything else you want us to know about priapism? PRIAPSM

Read the following statement: Thank you for helping us with this study about priapism. Here is a pamphlet with more information. Please let me or any of the clinic staff know if you have any questions about priapism or sickle cell disease. In the future our center may be part of a nationwide study of medicine by mouth to prevent priapism.

Q20NA

20. May we contact you about future studies of priapism? Yes No CONTACT

Be sure to complete the NIH Ethnicity/Race CRF for all participants, even those who choose not to attempt the survey.

The following section is for the interviewer and should not be read to the patient/parent/guardian.

21. Who was present during the interview? Patient alone Parent/guardian alone Patient and parent/ guardian
PRESENT
22. Who answered the above questions? Patient alone Parent/guardian alone Patient and parent/ guardian together
ANSWER
23. In what context did the interview occur? CNTXT
- Urgent Care Visit Routine Visit Health Fair Callback
- Chronic Transfusion Hydroxyurea Other, specify: CNTXTSP

Please answer demographic questions about yourself. (check those that apply)

- GENDER
24. Gender: Male Female
- AGE
25. Age: ≤ 30 years 31-49 years ≥ 50 years
- INTETH
26. Ethnicity: Hispanic or Latino Not Hispanic or Latino
- INTAMIN
27. Race: American Indian / Alaskan Native Native Hawaiian / Other Pacific Islander
(check all that apply) Asian INTASIA White INTWHITE
INTAFAM Black or African American INTOTR Other, specify: INTOTRS

PI Signature: SIGNTRE

Signature Date: SIGDA / SIGMO / SIGYR
Day Month Year
SIGDT