The elements on this form capture the Sickle cell related acute pain episodes data that should be collected. The items with astericks (\*) are Core and should be collected on all genetic studies in sickle cell disease assessing acute painful episodes. The others are Supplemental and should be collected based on study design.

Analgesic use (Prior and Concomitant Medication CRF will capture)

Long acting – which med and how many a month used

Short acting – which med and how many a month used.

**PAIN FREQUENCY**

1. \*In the last 12 months, has participant used an After Hours/Urgent Care Clinic/day hospital/infusion clinic or Emergency Room due to vaso-occlusive crisis (sickle cell related acute pain episode)?

Yes

No

Don’t know

* + 1. \*Number of inpatient admissions for vasoocclussive crisis or VOC (sickle cell related acute pain episode) in last 12 months \_\_\_\_\_\_\_
       1. Dates\_\_\_ \_\_\_ - \_\_\_ \_\_\_ \_\_\_ - \_\_\_ \_\_\_ \_\_\_ \_\_\_ (DD-MMM-YYYY)
       2. Length of stay each \_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_
    2. \*Number of treat and release day hospital/ infusion room visits for VOC/ 12 months \_\_\_\_\_\_\_\_\_\_
    3. \*Number of treat and release ED visits for VOC/ 12 months \_\_\_\_\_\_\_\_\_\_\_\_

1. \*Total Acute care utilization/ 12 months (sum of above 3) \_\_\_\_
2. Total number of SCD related ambulatory visits to sub-specialty or primary care/ 12 months \_\_\_\_
3. ED reliance in last 12 months #: ED visits/ (ED visits + ambulatory visits), where “ED visits” are only those leading to admission \_\_\_\_\_\_\_\_\_\_\_\_
4. Number of days inpatient for VOC in last 12 months: \_\_\_\_

\* Core CDE

## General Instructions

The elements on this form capture the Sickle cell related acute pain episodes data that should be collected. The items with astericks (\*) are Core and should be collected on all genetic studies in sickle cell disease assessing acute painful episodes. The others are Supplemental and should be collected based on study design.

Analgesic use (Prior and Concomitant Medication CRF will capture)

Long acting – which med and how many a month used

Short acting – which med and how many a month used.

These elements should be collected but not on this form:

1. Number of VOC patient had in the last 12 months that they treated at home
2. How many days of work/school was missed due to pain in the last 12 months?
3. What are the painful sites of your typical crisis
4. \*Do you have chronic pain?
5. What are the painful sites of your chronic pain?

## Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

#Hemker et al Am J Hematol, 2011 Oct;86(10):863-5. PMID: 21815184

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\*Core CDE