1. Date last known alive: |\_\_\_|\_\_\_|-|\_\_\_|\_\_\_|-|\_\_\_|\_\_\_|\_\_\_|\_\_\_| **→ STOP, complete Follow-up Form up to this date**

Month Day Year

1. Date of death: |\_\_\_|\_\_\_|-|\_\_\_|\_\_\_|-|\_\_\_|\_\_\_|\_\_\_|\_\_\_| **CONTINUE and complete Follow-up Form up to this date**

Month Day Year

1. Place of Death:  Hospital  Home  Community  Hospice  Other, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. \*Cause of Death on death certificate (add ICD-10-CM Codes Supplemental-Highly Recommended)

\*Primary cause: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\*Secondary cause(s): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Death certificate Not Available

1. Other sources of Cause of Death (check **all** that apply)

No Other Sources  Family Member  Medical Record  Autopsy Report

| Cause of Death from other sources (identify in consultation with PI) | Primary/  Immediate Cause  (check one) | Secondary/  Underlying or Comorbid Causes  (check all that apply) |
| --- | --- | --- |
| Acute Chest Syndrome |  |  |
| Respiratory Failure |  |  |
| Sudden Death |  |  |
| Infection |  |  |
| Stroke, Ischemic |  |  |
| Stroke, Hemorrhagic |  |  |
| Cardiac Arrest |  |  |
| Sickle Cell Disease Multiorgan Failure Syndrome |  |  |
| Kidney Failure |  |  |
| Liver Failure |  |  |
| Pulmonary Embolism |  |  |
| Trauma |  |  |
| Cancer (specify type, location): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |
| Other primary (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |
| Other secondary (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |

1. Is an autopsy report available? (copies of autopsy reports should be maintained locally)  Yes No

## General Instructions

Important note: *Core elements are indicated by asterisks (\*). All other data elements are classified as Supplemental (i.e., non Core) and should only be collected if the research team considers them appropriate for their study. Please see the Data Dictionary for element classifications.*

## Specific Instructions

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

**Cause(s) of Death** - Record the cause or causes of death using explanatory text and the associated ICD-10-CM code. Include the primary cause of death first followed by any secondary causes.

**Reference**

Sickle Cell Implementation Consortium