## COOPERATIVE STUDY OF SICKLE CELL DISEASE DISPOSITION UPDATE FORM - ADULT

	Person co	mpleting form (Name	)			Initials   _	
12	CSSCD C	code Number of person	n completing form (if k	(if known):  _ _ _			
3.	Date form	n completed (Month, I	Day, Year)				
PLEAS	E ANSWE	ER THE FOLLOWIN	G QUESTIONS ABO	UT THE PA	TIENT	'S CURRENT STATUS:	
i.	Is the pat	ient alive?	1. NO ↓		2. YES	9. DK	
		4.1. Date of death (M  * COMPLETE D	onth, Day, Year) EATH FORM. GO TO QU	//	•	4.2. Year last known to be alive:  19   _	
5.	Do you h	ave: a. Patient's cu	rrent address?	1. NO		2. YES ↓	
					5.1 5.2 5.3	City:	
6.	Is the pat		rrent telephone number llowed at your center?			<ol> <li>YES</li> <li>N/A (No Phone)</li> <li>YES</li> </ol>	
					lowed a	at another CSSCD center?	
7.	1. I 2. I 3. I	Patient moved outside Patient is refusing beca Patient is refusing for of Patient is in nursing ho	nuse he/she is being follother reason. → 7.1 Some or other chronic ca	lowed at anot Specify reasor are facility.	her hea	RESPONSE):  alth care facility within the area.  (s) because of illness.	

## \*\* PATIENT INTERVIEW SECTION \*\*

8.	Was patient interviewed?	1. No				YES		
		ļ						
	GO TO QUESTION 18		TON 18					
9.	Date of interview (Month, Day, Year)							
	* QUESTIONS 10 - 17 MAY BE ANSWEI	RED BY PATIENT IN CLINIC OF	R IN A TELEPHONE INTERVI	EW *				
10.	Are you able to walk up 10 steps without h another person, including people who live w other than the stair rail.			1. NO	2.	YES		
11.	Do you use any of the following, at least some	times, to get around?	A. Wheelchair?	1. NO	2.	YES		
	2000 Commence (1900 Commence C		B. Walker?	1. NO	2.	YES		
			C. 4-pronged cane?	1. NO				
			D. Single cane?	1. NO				
			E. Leg brace?	1. NO				
			F. Crutches? G. Other?	1. NO 1. NO				
			o. other:	1. NO	2.	1123		
			11.1 Specify:		1			
			Till oponiy.					
12.	Are you able to dress yourself, including shoe	s and socks, without help?						
	1.	NO 2. YES	8. NOT APPL	ICABLE	AN	<b>APUTE</b>		
13.	How much of the time are you healthy enough to be able to do the things you would like to be doing? Would you say							
	1. ALL OF THE TIME 2. MOST OF THE TIM	E 3. SOME OF THE TIME	4. ALMOST NEVER	5. NEV	ER			
14.	How would you rate your health as compared to others your age? Would you say it is							
	1. MUCH BETTER 2. SOMEWHAT BETT	TER 3. SAME	4. SOMEWHAT WORSE	5. MU	CHY	WORSE		
15.	How would you rate your health in general as compared to others with sickle cell disease? Would you say it is							
	1. MUCH BETTER 2. SOMEWHAT BETT	TER 3. SAME	4. SOMEWHAT WORSE	5. MU	CH.	WORSE		
	QUESTION	16 REFERS TO THE FOLI	LOWING SCALE					
	1 = No Symptoms							
	2 = Minor Symptoms: Minimal disruption of lifestyle (10 days or less in past 6 months)							
	3 = Mild Symptoms: Intermittent problems requiring confinement to home or hospital (More than 10 days in past 6 mo							
	4 = Moderate Symptoms: Often unable to carry on normal activities							
	5 = Severe Symptoms: Severely disabled, in need of care most of the time							
	5 - Severe symptoms.	toled, in need of each most of the	Title .					
16.	How would you rate the extent to which sickle	e cell disease has affected yo	our life in the past 6 month	hs?				
	Ra	ating:						
17.	Are you currently employed for pay? 1.	NO 2. YES						

1. NO 2. YES

			Page 3	311 A 03/	91
18.	Reaso	n patient not interviewed (CHECK ONLY 1 RESPONSE)			
	1.	Patient was unable to complete interview because of mental or physical disability			
	2.	Patient refused to complete interview			
	3.	Patient could not be contacted			
	4.	Other reason			
		18.1 Specify reason			
	5.	N/A - Interview completed			
19.		resources did you use to try to establish contact with patient or to determine patient's vital stack NO OR YES FOR EACH OF A - T)	atus?		
	A.	Patient address/telephone information on file in office or in hospital chart	1. NO	2. YES	S
	B.	Relative of patient	1. NO	2. YE	S
	C.	Friend of patient	1. NO	2. YE	S
	D.	Other medical facility or clinic	1. NO	2. YE	S
	E.	Employer	1. NO	2. YE	S
	F.	School or Board of Education	1. NO	2. YE	S
	G.	Hospital Social Services Department	1. NO	2. YE	S
	H.	Standard Telephone Directory	1. NO	2. YE	S
	I.	Telephone directory organized by address	1. NO	2. YE	S
	J.	Neighbor/Landlord	1. NO	2. YE	S
	K.	Postal Service search	1. NO	2. YE	S
	L.	Vital Statistics records *	1. NO	2. YE	S
	M.	Voter Registration records *	1. NO	2. YE	S

19.1 Specify:

Other

Department of Motor Vehicles records

Social Security Administration

Public Aid Department

Public utility company

Medical Examiner's Office

Equifax Support Services

N.

O.

P.

Q.

R.

S.

T.

<sup>\*</sup> public records

Rating |\_\_|

## \*\* PHYSICIAN'S ASSESSMENT OF PATIENT'S HEALTH \*\*

\*\* QUESTIONS 20-21 ARE TO BE ANSWERED BY STUDY PERSONNEL MOST FAMILIAR WITH PATIENT'S MEDICAL HISTORY \*\*

Has the patient ever been diagnosed with:							
(CHECK NO OR YES FOR EACH OF A-F)							
A.	Stroke		1. NO 2	2. YES			
B.	Aseptic Necrosis		1. NO 2	2. YES			
C.	Asthma or other chro	ic lung disease	1. NO 2	2. YES			
D.	Chronic heart disease		1. NO 2	2. YES			
E.	Chronic liver disease		1. NO 2	2. YES			
F.	Chronic renal disease		1. NO 2	2. YES			
	QUESTION 21 REFERS TO THE FOLLOWING SCALE						
1 = No Symptoms							
	= Minor Symptoms:	Minimal disruption of lifestyle (10 days or less	in past 6 months )				
				C mantha)			
3 = Mild Symptoms:		Intermittent problems requiring confinement to home or hospital (More than 10 days in past 6 months)					
	= Moderate Symptoms:	Often unable to carry on normal activities					
	= Severe Symptoms:	Severely disabled, in need of care most of the t	time				
7 =	= Not Applicable:	Patient died more than 6 months ago					
9 =	= Unknown:	Patient not seen for more than 6 months					

Rate the overall degree of disability of the patient for the past 6 months:

21.