#### 7.6.0: Acute Anemic Events - Overview

### A. CSSCD Forms (collection) and Datasets (storage) Relating to Event:

Form #	Name of Form	Collected	Patient Population	SAS Dataset
46	Acute Anemic Episode and Splenic Sequestration Form	03/01/79- 05/31/86	All	R46.SD2
		06/01/86- 12/31/86	Patients entered at < 6 months of age.	
53	Comprehensive Special Event Form for Patients Entered < 6 Months of Age	01/01/87- 09/30/88	Patients entered at < 6 months of age.	R53.SD2
47	Acute Anemic Episode Flow Sheet	03/01/79- 12/31/86	All Acute Anemic Episodes if patient hospitalized or seen daily	R47.SD2
52	Acute Event Treatment Follow-up	03/01/79- 12/31/86	All Acute Anemic Episodes	R52.SD2

### B. <u>Definition of the Event</u>:

Acute Anemic Episode: (See Section 7.6.1)

A reduction in hemoglobin or hematocrit of at least 30% not caused by blood loss or a transfusion reaction, or reduction of hemoglobin level by 20% accompanied by acute increase in spleen size.

Acute anemic events were to be classified into one of the following three categories:

- 1. <u>Splenic sequestration crisis</u>: Increase in spleen size and firmness, reduction of hemoglobin level by at least 20%.
- 2. Aplastic crisis: Decrease in reticulocyte count before or concurrent with falling hemoglobin level (> 30% reduction from usual level), fall in platelet count and white cell count in prolonged aplasia, and appearance of increased nucleated red cells and reticulocytes in peripheral blood as the marrow recovers.
- 3. <u>Hyperhemolytic crisis</u>: Normal or increased reticulocyte counts and nucleated RBC counts during an episode of falling hemoglobin and increase in indirect bilirubin level over the usual value.

### 7.6.1: Acute Anemic Episode and Splenic Sequestration Form – Form 46

# A. <u>List of variables deleted</u> **F46DATE F46INIT F46NDATE F46LASTU F46LASTE F46ESTAT F46VDATE F46DFC F46FCB F46LSTDT F46PRDT F46MMD1-F46MMD3 F46PEB F46LABDT**

- B. List of variables modified **NONE**
- C. List of variables modified with a name change **NONE**
- D. Old name
- E. New name
- F. List of variables modified date to days since DOE
- G. Old name F46DATE F46LSTDT F46PRDT
- H. New name JF46DATE J46LSTDT JF46PRDT
- I. Collection Information:

Form 46 (Acute Anemic Episode and Splenic Sequestration Form) was completed each time a study patient presented at a study participant clinic, emergency room, or hospital with an acute anemic event (per definition), which was not caused by blood loss or a transfusion reaction.

J. Data Collection Period: 03/79 - 12/86

Form 46 was used between 03/79 and 12/86 for all cohorts and continued to be used for patients entered at < 6 months of age through 12/86.

K. Form Version Dates: 03/01/79, 03/29/79, 09/25/80, 03/12/82

Not all information from all form versions was retained to the final dataset. Variables considered unimportant or unusable from early forms were permanently dropped from the final dataset. Consequently the codebook coincides with the latest version of Form 46.

L. Files Used to Store Information:

SAS System File: R46.SD2

Format File: R46.FMT

M. Unique Record Identifiers: ANONID, F46DATE

Records within the dataset are sorted by **ANONID** and **F46DATE**.

- N. Number of Observations (Patients) in SAS Dataset: 642 (472)
- O. Contents of SAS Dataset:
  - Alphabetical Listing of Variables: See pp. 603-605

Listing of Variables by Position: See pp. 606-608

#### P. Notes About Selected Variables:

- **F46EVENT** is a concatenated numeric variable consisting of 4 2-digit codes which identify other event forms completed in addition to the Form 46. Values are left justified, so that if fewer than 4 other forms are filled out, there will be trailing zeros. For example, a value of "32000000" means that the only form filled out in addition to the Form 46 is a Form 32 (Acute Chest Syndrome).
- F46TYPE is the variable name for type of acute anemic event. Although the
  form was not supposed to be used for anemic events resulting from blood loss, a
  response choice for this cause was included on the form, and forms completed
  for blood loss were accepted to the database.
- F46CBCWB is the CBC White Blood Cell Count variable assumed to be "uncorrected" in relation to nucleated red blood cells (RBCs). There is a question as to whether clinics uniformly adhered to this recording policy, and there is no way of knowing whether the values recorded on the form are in fact uncorrected.
- F46NRB is the Nucleated Red Blood Cell variable. The field length is 2-digits.
   If there were more than 100 nRBCs/100 WBC, then a value of 99 was entered.
- **F46PRBC** is the variable name for pocked RBC count. Test results for all PRBC counts completed during the study are stored in **R07.SD2** (See Section 5.2)—i.e., additional results for tests done at the time of an event may exist in this dataset.

#### Q. Computed Variables:

- F46FLOWS is the number of follow-up hospitalization or "flow" sheets, in this
  case form 47 sheets, associated with a given Form 46. It was derived by linking
  "Record 47" with "Record 46" by date (F47DATE with F46DATE) patient first
  sought care.
- **F46DHOSP** is the number of days that data was collected on hospitalized acute anemic episodes. The number was derived by linking "Record 46" with all "Record 47s" for date care was sought (**F46DATE** with **F47DATE**) and counting all the mo/day variables on Form 47 that were not missing for a given hospital stay (i.e., will equal # of days hospitalized if forms were filled in correctly).
- F46FRM52 is the type code associated with a Form 52 (Acute Event treatment Follow-up) with the same date as the acute anemic event (F52DATE, F46DATE).

The **F46FRM52** variable was made equal to **F52TYPE** with the same date care was sought. If treatment and follow-up information were included on Form 31 because the event was associated with a pain event, the value of **F46FRM52**=31, and "Record 46" should be linked with "Record 31" for this information (i.e., if **F46DATE=F31DATE**). If treatment and follow-up information were included on Form 33 because the event was associated with an ACS event the value of **F46FRM52**=33, and "Record 46" should be linked by date patient first sought care for this information (i.e., if **F46DATE=F33DATE**).

#### R. Inter-Relationship with Other Datasets:

1. Acute Anemic Episode data were also collected on

Phase 1 SAS Dataset Form 53 R53.SD2

[See Section 7.9]

Phase 2 & 3 Forms SAS Dataset Form "NCVA" NCVA\_PST.SD2

[See Section B]

Form 53, the Comprehensive Special Event Form for Patients Entered at < 6 Months of Age, stored in **R53.SD2**, was used to continue collection of acute anemic episode information on the newborn cohort from 1/1/87 through the end of Phase 1. This form was used to record information about both hospitalized and non-hospitalized acute anemic events.

2. Follow-up and treatment information were collected on

Phase 1 Forms SAS Dataset
Form 47 R47.SD2
Form 52 R52.SD2

Both of the above mentioned records should be linked to the appropriate acute anemic event "Record 47" by the date of the anemic episode (i.e., if **F47DATE=F46DATE**, or if **F52DATE=F46DATE**).

a. Form 47 is the Acute Anemic Episode Flow Sheet. Form 47 data are stored in R47.SD2. The form was completed if the patient was either hospitalized or seen on a daily basis as an outpatient for an acute anemic episode. It contains daily and summary information from day 2 of hospitalization for the event through discharge. Each "Record 47" contains 6 days of hospital

information, so consequently, multiple "Record 47s" could exist for a given episode, dependent on length of stay.

"Record 47s" are sorted by **ANONID**, **F47DATE**, and flow sheet number **F47SHEET**. Therefore, information for hospital days 2-7 should be on **F47SHEET**=1; days 8-13 on **F47SHEET**=2, etc.

b. Form 52 is the Acute Event Treatment Follow-up form stored in R52.SD2 that was used to collect information on event treatment, resolution of symptoms, and diagnosis. The form was used between 03/79 and 12/86. In order to link a specific "Record 46" with a "Record 52," the date patient first sought care is used (i.e., F52DATE=F46DATE). When the treatment information is not stored in F52.SD2, but rather in F31.SD2 (F46FRM52=31) or F33.SD2 (F46FRM52=33), "Record 46" should be linked by date to "Record 31" or "Record 33" respectively for treatment, resolution of symptoms, and diagnostic data (i.e., if F46FRM52=31, the F31DATE=F46DATE, if F46FRM52=33, then F33DATE=F46DATE).

CSSCD FULL COHORT PATIENTS

#### CONTENTS OF SAS DATASET: R46.SD2

DATA FROM CSSCD FORM 46 - ACUTE ANEMIC EPISODE AND SPLENIC SEQUESTRATION FORM VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
The SAS System 16:42 Tuesday, January 30, 2007 1

#### The CONTENTS Procedure

Data Set Name	OUT1.R46	Observations	642
Member Type	DATA	Variables	77
Engine	V9	Indexes	0
Created	14:10 Friday, January 19, 2007	Observation Length	616
Last Modified	14:10 Friday, January 19, 2007	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			

Data Representation WINDOWS

Encoding wlatin1 Western (Windows)

#### Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	26
First Data Page	1
Max Obs per Page	26
Obs in First Data Page	10
Number of Data Set Repairs	0

File Name r46.sas7bdat
Release Created 9.0000M0
Host Created XP\_PRO

#### Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
63	F46ANTIC	Num	8	ANTI C3
60	F46BLRBN	Num	8	INDIRECT BILIRUBIN
37	F46CBCHB	Num	8	CBC HB
38	F46CBCHC	Num	8	CBC HCT
41	F46CBCMV	Num	8	CBC MCV
39	F46CBCRB	Num	8	CBC RBC
40	F46CBCWB	Num	8	CBC WBC
65	F46CELL	Num	8	ESTIMATED CELLULARITY
61	F46COMBS	Num	8	DIRECT COOMBS
59	F46DBLRB	Num	8	DIRECT BILIRUBIN
50	F46DFATC	Num	8	DIFFERENTIAL ATYPICAL CELLS
47	F46DFBAS	Num	8	DIFFERENTIAL BASOPHILS
45	F46DFBND	Num	8	DIFFERENTIAL BANDS
46	F46DFE0S	Num	8	DIFFERENTIAL EOSINOPHILS
48	F46DFLYM	Num	8	DIFFERENTIAL LYMPHOCYTES
51	F46DFMM	Num	8	DIFFERENTIAL METAMYELOCTYES   MYELOCYTES
49	F46DFMON	Num	8	DIFFERENTIAL MONOCYTES
44	F46DFPMN	Num	8	DIFFERENTIAL PMN
74	F46DH0SP	Num	8	NUMBER OF DAYS HOSPITALIZED
16	F46DRGS	Num	8	DRUGS TAKEN WITHIN LAST WEEK

2	F46EVENT	Num	8	ASSOCIATED EVENTS
57	F46FE	Num	8	FE
58	F46FERR	Num	8	FERRITIN
72	F46FL0WS	Num	8	NUMBER OF FLOW SHEETS
55	F46F0LIC	Num	8	FOLIC ACID
73	F46FRM52	Num	8	IS THERE A FORM 52 ON THE DATABASE
71	F46HBS	Num	8	HB S %
42	F46HJB	Num	8	HOWELL JOLLY BODIES
3	F46H0SP	Num	8	HOSPITALIZED
62	F46IGG	Num	8	ANTI IGG
67	F46IRON	Num	8	IRON STORES
70	F46LSC	Num	8	LIVER-SPLEEN SCAN
7	F46LSTHB	Num	8	LAST ROUTINE HB
6	F46LSTHC	Num	8	LAST ROUTINE HCT
30	F46LVRSZ	Num	8	SIZE OF LIVER
31	F46LVRTN	Num	8	LIVER TENDERNESS
24	F46MDT1	Num	8	MEDICATION DAYS TAKEN
26	F46MDT2	Num	8	MEDICATION DAYS TAKEN
28	F46MDT3	Num	8	MEDICATION DAYS TAKEN
23	F46MED1	Num	8	MEDICATION CODE
25	F46MED2	Num	8	MEDICATION CODE
27	F46MED3	Num	8	MEDICATION CODE
17	F46MEDD1	Num	8	MEDICATION TAKEN - CODE
18	F46MEDD2	Num	8	MEDICATION TAKEN - CODE
19	F46MEDD3	Num	8	MEDICATION TAKEN - CODE
20	F46MEDD4	Num	8	MEDICATION TAKEN - CODE
69	F46MMAT	Num	8	MEGALOBLASTIC MATURATION
66	F46MYEY	Num	8	MYELOID-ERYTHROID RATIO
64	F46NECR	Num	8	NECROSIS
68	F46NMAT	Num	8	NORMOBLASTIC MATURATION
52	F46NRB	Num	8	NUCLEATED RED BLOOD CELLS
36	F460PHYS	Num	8	OTHER PHYSICAL FINDINGS
53	F46PLATE	Num	8	PLATELETS
43	F46PRBC	Num	8	POCKED RBC
9	F46PRHB	Num	8	PRESENT HB
8	F46PRHC	Num	8	PRESENT HCT
11	F46RDHB	Num	8	REDUCTION HB
10	F46RDHC	Num	8	REDUCTION HCT
54	F46RETIC	Num	8	RETICULOCYTES
34	F46SPLDI	Num	8	SPLEEN CM FROM MIDLINE
32	F46SPLP	Num	8	PALPABLE SPLEEN
35	F46SPLTN	Num	8	SPLEEN TENDERNESS
33	F46SPLTP	Num	8	SPLEEN TIP PALPATED (CM)
15	F46SYMBL	Num	8	SYMPTOMS BLEEDING
13	F46SYMFI	Num	8	SYMPTOMS FEVER-DIAGNOSED INFECTION
12	F46SYMPE	Num	8	SYMPTOMS-PAINFUL EPISODE
14	F46SYMVD	Num	8	SYMPTOMS VOMITING-DIARRHEA
56	F46TIBC	Num	8	TIBC
4	F46TRANS	Num	8	TRANSFUSED
22	F46TREVT	Num	8	TRANSFUSION FOR EVENT
21	F46TRNS	Num	8	TRANSFUSION IN LAST WEEK
5	F46TYPE	Num	8	TYPE OF DIAGNOSIS
29	F46WGT	Num	8	WEIGHT (KG)
76	J46LSTDT	Num	8	LAST ROUTINE DATE - RECODE DAYS SINCE DOE
75	F46DATE	Num	8	DATE FIRST SOUGHT CARE - RECODE DAYS SINCE DO

77 JF	46PRDT	Num	8 PRESE	NT DATE - REC	ODE DAYS SINCE	E DOE	
* R46.FN categori * variak *	MT contarical * oles in t	ins val	ue labels dataset	s for numer	********** rical codes	assigned	to
* SIR/DE	BMS 2.2 S	SAS PRO	C STEP FF	ROM DATABAS	SE: CSSCD	11/14/98	11:15:07;
PROC FOR	RMAT;						
* FOF		YES use	d for the	e following	y variables	: F46HOSP :	F46TRANS
VALUE 1 2	NO_YES		'NO' 'YES';				
VALUE 1 2 3 4	F46TYPE	=	'APLASTIC	MOLYTIC CRI			
* FORMA F46SYMVI		ES used	for the	following	variables:	F46SYMPE	
VALUE 1 2 3	NODKYES	=	'NO' 'DK' 'YES';				
VALUE 1 2 3	F46TREV	=	'NO' 'YES' 'DK';				
	AT ABS_PI N F46HJB		used for	the follow	<i>i</i> ing variab	les: F46LV	RTN
VALUE 1 2	ABS_PRES	=	'ABSENT'	';			

```
* FORMAT RESULT is used for the following variables: F46COMBS F46IGG
F46ANTIC;
 VALUE RESULT
   1
                   = 'POSITIVE'
   2
                  = 'NEGATIVE';
* FORMAT YES_NO is used for the following variables: F46NECR F46MMAT;
 VALUE YES NO
                   = 'YES'
   1
   2
                   = 'NO';
 VALUE F46IRON
                   = 'PRESENT'
   1
   2
                   = 'ABSENT';
 VALUE F46NMAT
                   = 'NORMAL'
   1
                  = 'ABNORMAL';
   2
 VALUE F46LSC
   1
                  = 'DONE'
   2
                  = 'NOT DONE';
* FORMAT
        F46HOSP F46TRANS F46TRNS F46SPLP F46OPHYS NO_YES.
        F46TYPE F46TYPE.
        F46SYMPE F46SYMFI F46SYMVD F46SYMBL F46DRGS NODKYES.
        F46TREVT F46TREVT.
        F46LVRTN F46SPLTN F46HJB ABS_PRES.
        F46COMBS F46IGG F46ANTIC RESULT.
        F46NECR F46MMAT YES NO.
        F46IRON F46IRON.
        F46NMAT F46NMAT.
        F46LSC F46LSC.;
RUN;
QUIT;
```

CSSCD FULL COHORT PATIENTS

F46VDATE ----- VERSION DATE DELETED type: numeric daily date (int) label: datelab range: [6999,8106] units: 1 or equivalently: [01mar1979,12mar1982] units: days unique values: 4  $\,$  coded missing: 0 / 642 tabulation: Freq. Numeric Label 6999 03/01/79 59 7027 03/29/79 1 568 14 568 7573 09/25/80 8106 03/12/81 F46EVNT1 ----- ASSOCIATED EVENT CODE 1 type: numeric (float) range: [0,91] units: 1 unique values: 21 coded missing: 81 / 642 tabulation: Freq. Value 1 0 74 30 1 31 59 32 1 33 6 34 3 36 1 38 3 40 2 44 44 47 70 48 1 49 1 52 68 54 6 62 1 71 5 83 202 84 10 90 2 91

#### F46EVNT1:

 Computed variable: F46EVNT1=int(F46EVENT/1000000), not stored in the .SD2 file.

CSSCD FULL COHORT PATIENTS

		,,	numeric (float)						
		range:	[0,91]	u	nits:	1			
	unique	values:	25	coded mis	sing:	81	/	642	
tabula	tion:								
req.	Value			Freq.	Valu	е			
217	0			10					
1	13			50	48				
5	30			11	49				
12	31			13	52				
36	32			29	54				
5	33			1	58				
8	34			3	62				
1	35			7					
11	36			, 125					
	38			2					
	40			3					
-	45			2					
				2	51				
1.	Computed v	the .SD2							
746EVN 1.	Computed v	the .SD2							
746EVN 1.	Computed v	the .SD2  type:	file.  numeric (float)		ASSOC	CIAT			
746EVN 1.	Computed vistored in	the .SD2	numeric (float)		ASSOC	CIAT	ED	EVEN	
1. 1.	Computed vistored in	the .SD2 type: range:	numeric (float)		ASSOC	CIAT	ED	EVEN	
-46EVN 1. -46EVN	Computed vistored in T3unique	the .SD2 type: range:	numeric (float)	u coded mis	ASSOC nits: sing:	1 81	ED	EVEN	
F46EVN 1. F46EVN tabula Freq.	Computed vistored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq.	ASSOC nits: sing: Valu	1 81	ED	EVEN	
F46EVN  1.  F46EVN  tabula  req. 391	Computed vistored in T3 unique tion: Value 0	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13	ASSOC nits: sing: Valu 47	1 81	ED	EVEN	
F46EVN  1.  F46EVN  tabula  req. 391 1	Computed vistored in T3 unique tion: Value 0 12	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15	ASSOC nits: sing: Valu 47 48	1 81	ED	EVEN	
tabula req. 391	Computed vistored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7	ASSOC nits: sing: Valu 47 48 49	1 81	ED	EVEN	
F46EVN 1. F46EVN tabula Freq. 391 1 1 2	computed vistored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7	ASSOC nits: sing: Valu 47 48 49 50	1 81	ED	EVEN	
f46EVN 1. f46EVN tabula freq. 391 1 1 2 1	Computed of stored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7 1	ASSOC nits: sing: Valu 47 48 49 50 52	1 81	ED	EVEN	
tabula=req. 391 1 2 1 8	Computed of stored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7 1 12	ASSOC nits: sing: Valu 47 48 49 50 52 54	1 81	ED	EVEN	
tabula Freq. 391 1 2 1 8 5	computed of stored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7 1 12 12 12	ASSOC nits: sing: Valu 47 48 49 50 52 54 62	1 81	ED	EVEN	
tabula Freq. 391 1 2 1 8 5	computed of stored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7 1 12 12 3 1	ASSOC nits: sing: Valu 47 48 49 50 52 54 62 71	1 81	ED	EVEN	
tabula req. 391 1 2 1 8 5 5	computed of stored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7 1 12 12 3 1 2	ASSOC nits: sing: Valu 47 48 49 50 52 54 62 71 83	1 81	ED	EVEN	
tabula Freq. 391 1 2 1 8 5 3	Computed of stored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7 1 12 12 3 1 2 70	ASSOC nits: sing: Valu 47 48 49 50 52 54 62 71 83 84	1 81	ED	EVEN	
tabula req. 391 1 2 1 8 5 5	computed of stored in T3	the .SD2 type: range:	numeric (float)	u coded mis Freq. 13 15 7 1 12 12 3 1 2	ASSOC nits: sing: Valu 47 48 49 50 52 54 62 71 83	1 81	ED	EVEN	

 Computed variable: F46EVNT3=int((F46EVENT-F46EVNT1\*1000000-F46EVNT2\*10000)/100), not stored in the .SD2 file.

CSSCD FULL COHORT PATIENTS

F46EVNT4 ----- ASSOCIATED EVENT CODE 4 type: numeric (float) range: [0,96] units: 1 coded missing: 81 / 642 unique values: 15 tabulation: Freq. Value 483 0 2 4 1 20 1 28 6 32 1 36 3 44 19 48 6 52 2 54 3 56 29 84 1 88 1 92 3 96 F46EVNT4: 1. Computed variable: F46EVNT4=(F46EVENT-F46EVNT1\*1000000-F46EVNT2\*10000-F46EVNT3\*100), not stored in the .SD2 file. F46HOSP ----- HOSPITALIZED type: numeric (float) label: F46HOSP range: [1,2] units: 1 unique values: 2 coded missing: 0 / 642 tabulation: Freq. Numeric Label 1 NO 22 2 YES 620 F46TRANS ----- TRANSFUSED type: numeric (float) label: F46TRANS range: [1,2] unique values: 2 units: 1 coded missing: 61 / 642 tabulation: Freq. Numeric Label 362 1 NO 219 2 YES

CSSCD FULL COHORT PATIENTS

F46TYPE ----- TYPE OF DIAGNOSIS

type: numeric (float)

label: F46TYPE

units: 1 range: [1,4]

coded missing: 105 / 642 unique values: 4

tabulation: Freq. Numeric Label

1 SPLENIC SEQUESTRATION 132

2 APLASTIC CRISIS 266

130 9 3 HYPERHEMOLYTIC CRISIS 130

4 BLOOD LOSS

CSSCD FULL COHORT PATIENTS

F46LSTHC ----- LAST ROUTINE HCT

type: numeric (float)

range: [13,45] units: .1 values: 150 coded missing: 19 / 642 unique values: 150

mean: 24.8295 std. dev: 4.98648

percentiles: 10% 25% 50% 75% 19 21 24 27.2 90%

31.9

F46LSTHB ------ LAST ROUTINE HB

type: numeric (float)

range: [4.8,14.1] units: .1 unique values: 79 coded missing: 19 / 642

mean: 8.40562 std. dev: 1.53473

percentiles: 10% 25% 50% 75% 90% 6.7 7.3 8.2 9.2 10.6

F46PRHC ----- PRESENT HCT

type: numeric (float)

range: [6,36] units: .1 values: 132 coded missing: 10 / 642 unique values: 132

mean: 15.4332 std. dev: 4.09056

percentiles: 10% 25% 50% 75% 90% 10.5 13 15 17.45 20

F46PRHB ------ PRESENT HB

type: numeric (float)

range: [1.7,11.7]

units: .1 coded missing: 8 / 642 unique values: 69

mean: 5.24574 std. dev: 1.30917

percentiles: 10% 25% 50% 75% 90% 3.6 4.4 5.2 5.9 6.9

CSSCD FULL COHORT PATIENTS

F46RDHC ----- REDUCTION HCT type: numeric (float) range: [-19,79] units: 1 values: 74 coded missing: 25 / 642 unique values: 74 mean: 37.0746 std. dev: 13.8917 percentiles: 10% 25% 50% 75% 90% 21 29 36 45 57 F46RDHB ----- REDUCTION HB type: numeric (float) range: [-21,82] units: 1 values: 74 coded missing: 22 / 642 unique values: 74 mean: 36.8694 std. dev: 13.7917 percentiles: 10% 25% 50% 75% 90% 22 29 36 45 56 F46SYMPE ----- SYMPTOMS-PAINFUL EPISODE type: numeric (float) label: F46SYMPE range: [1,3] units: 1 unique values: 3 coded missing: 4 / 642 tabulation: Freq. Numeric Label 304 1 NO 2 DK 3 YES 11 323 F46SYMFI ----- SYMPTOMS FEVER-DIAGNOSED INFECTION type: numeric (float) label: F46SYMFI range: [1,3] unique values: 3 units: 1 coded missing: 1 / 642 tabulation: Freq. Numeric Label 256 1 NO 19 2 DK 366 3 YES

CSSCD FULL COHORT PATIENTS

F46SYMVD ----- SYMPTOMS VOMITING-DIARRHEA

type: numeric (float) label: F46SYMVD

range: [1,3] units: 1

coded missing: 11 / 642 unique values: 3

tabulation: Freq. Numeric Label

500 1 NO 4 2 DK 127 3 YES

F46SYMBL ----- SYMPTOMS BLEEDING

type: numeric (float)

label: F46SYMBL

range: [1,3] units: 1 unique values: 3 coded missing: 7 / 642

tabulation: Freq. Numeric Label

603 1 NO 5 2 DK 27 3 YES

F46DRGS ----- DRUGS TAKEN WITHIN LAST WEEK

type: numeric (float)

label: F46DRGS

range: [1,3] units: 1
unique values: 3 coded missing: 4 / 642

tabulation: Freq. Numeric Label

259 1 NO

4 2 DK 375 3 YES

CSSCD FULL COHORT PATIENTS

F46MEDD1 ----- MEDICATION TAKEN - CODE type: numeric (float) range: [3,999] units: 1 values: 79 coded missing: 285 / 642 unique values: 79 tabulation: Freq. Value Freq. Value 5 3 1 335 5 6 8 337 3 7 2 338 1 11 1 361 1 21 2 367 1 23 6 369 3 370 6 25 1 26 30 371 31 28 2 374 2 29 4 375 1 37 1 391 1 41 1 420 3 44 431 3 56 443 2 57 449 1 59 1 452 1 67 1 462 1 94 1 471 2 102 42 480 4 126 26 481 37 171 1 484 4 190 490 4 191 3 512 4 192 3 515 1 230 1 519 6 231 1 528

### F46MEDD1:

1 299

1 237

2 239

36 249

1 259

1 279

1 280

1 284

1 289

2 290

2 304

1 306

1 240

1 248

- 1. Required only if F46DRGS=3.
- 2. See Appendix D for medication codes.

1 530

2 536

2 541

3 552

2 554

2 564

11 999

1 540

1 562

1 599

537

539

545

CSSCD FULL COHORT PATIENTS

F46MEDD2 ----- MEDICATION TAKEN - CODE

type: numeric (float)

range: [3,999] units: 1 values: 50 coded missing: 454 / 642 unique values: 50

tabula	tion:		
Freq.	Value	Freq.	Value
4	3	4	337
1	6	2	338
1	20	1	369
1	21	1	370
2	25	7	371
10	28	1	372
2	44	3	375
1	59	6	382
3	126	1	417
1	152	3	420
16	171	1	423
1	181	1	441
3	190	1	443
3	231	2	448
1	248	20	480
36	249	8	481
1	269	2	484
1	275	3	512
3	279	1	515
1	280	10	519
1	298	1	540
2	299	2	541
3	306	1	550
1	322	1	554
1	328	5	999

#### F46MEDD2:

- 1. Required only if F46DRGS=3 and >1 medication taken.
- 2. See Appendix D for medication codes.

CSSCD FULL COHORT PATIENTS

F46MED		numeric (float)		- MEDIC	ATION TAKE	N - CODE
	range: unique values:	[6,999] 44		units: ssing:	1 534 / 642	
tabula	tion:					
Freq.	Value		Freq.	Value		
2	6		1	342		
1	7		1	344		
2	25		2	369		
9	28		2	370		
1	59		3	371		
2	126		1	374		
1	156		2	375		
1	160		1	382		
6	171		1	417		
2	190		1	420		
1	191		2	436		
1	196		1	448		
1	230		1	467		
6	231		12	480		
1	240		10	481		

1 515

1 519

1 538

1 545

1 562

1 564

2 999

### F46MEDD3:

13 2491 275

1 298

2 304

1 328

1 335

3 337

- 1. Required only if F46DRGS=3 and >2 medications taken.
- 2. See Appendix D for medication codes.

CSSCD FULL COHORT PATIENTS

F46MEDD4 ----- MEDICATION TAKEN - CODE type: numeric (float) range: [3,998] units: 1 values: 28 coded missing: 590 / 642 unique values: 28 tabulation: Freq. Value Freq. Value 1 3 1 306 1 25 4 337 4 28 1 342 1 56 1 349 1 157 1 361 2 171 1 192 1 374 7 249 1 375 1 270 1 382 2 279 1 441 2 285 6 480 1 286 4 481 1 290 2 484 1 296 1 998 F46MEDD4: 1. Required only if F46DRGS=3 and >3 medications taken. 2. See Appendix D for medication codes. F46TRNS ----- TRANSFUSION IN LAST WEEK type: numeric (float) label: F46TRNS range: [1,2] units: 1 unique values: 2 coded missing: 2 / 642 tabulation: Freq. Numeric Label 1 NO 494 146 2 YES F46TREVT ----- TRANSFUSION FOR EVENT type: numeric (float) label: F46TREVT range: [1,3] units: 1 values: 3 coded missing: 277 / 642 unique values: 3 tabulation: Freq. Numeric Label

#### F46TREVT:

1. Required only if F46TRNS=2.

202 1 NO 161 2 YES 2 3 DK

161

	type:	numeric (float)		
	range:	[3,999]	units:	1
	unique values:	42	coded missing:	417 / 642
abula			Fran 1/al	
•	Value		Freq. Value 1 239	
	3 6		12 249	
	7		1 285	
1	20		1 337	
3	25		2 369	
12	28		1 370	
1	29		7 371	
1	33		1 374	
3	44		3 375	
1	94		1 396	
1	102		2 420	
1	126		1 449	
1	138		1 465	
2	160		1 471	
1	170		76 480	
14	171		29 481	
1	189		1 484	
2	190		1 536	
5	192		1 539	
1	211		1 562	
	231		11 999	
46MED	1:			
1.	See Appendix D for	medication codes.		
				NICATION DAVO TAK
46MDT	1		MHI	
46MDT		numeric (float)	MEL	DICATION DAYS TAK
46MDT		numeric (float)	MEL	JICATION DAYS TAK
46MDT		numeric (float)	units:	
F46MDT	type: range:	numeric (float)		1
-46MDT	type: range:	numeric (float)	units:	1
F46MDT	type: range:	numeric (float) [0,9] 10 Freq. Value	units:	1
F46MDT	type: range: unique values:	numeric (float) [0,9] 10 Freq. Value 2 0	units:	1
-46MDT	type: range: unique values:	numeric (float)  [0,9] 10  Freq. Value 2 0 70 1	units:	1
F46MDT	type: range: unique values:	numeric (float) [0,9] 10  Freq. Value 2 0 70 1 53 2	units:	1
F46MDT	type: range: unique values:	numeric (float)  [0,9] 10  Freq. Value 2 0 70 1 53 2 26 3	units:	1
-46MDT	type: range: unique values:	numeric (float)  [0,9] 10  Freq. Value 2 0 70 1 53 2 26 3 14 4	units:	1
-46MDT	type: range: unique values:	numeric (float)  [0,9] 10  Freq. Value 2 0 70 1 53 2 26 3 14 4 10 5	units:	1
-46MDT	type: range: unique values:	numeric (float)  [0,9] 10  Freq. Value 2 0 70 1 53 2 26 3 14 4 10 5 6 6	units:	1
-46MDT	type: range: unique values:	numeric (float)  [0,9] 10  Freq. Value 2 0 70 1 53 2 26 3 14 4 10 5 6 6 7 7	units:	1
-46MDT	type: range: unique values:	numeric (float)  [0,9] 10  Freq. Value 2 0 70 1 53 2 26 3 14 4 10 5 6 6	units:	1

	numeric (float)	MEDICATION CODE
2,601	(12000)	
range:	[1,999]	units: 1
unique values:		coded missing: 564 / 642
tabulation:		_
Freq. Value		Freq. Value
2 1		1 369
1 3		5 371
1 6		2 382
1 11		1 391
1 21		1 410
3 25		1 420
7 28		1 423
1 44		11 480
1 59		5 481
10 126		2 484
1 171		1 515
1 191		1 519
1 231		2 562
10 249		2 999
1 274		
F46MED2:		
1. See Appendix D for	medication codes.	
		MEDICATION DAYS TAKEN
type:	numeric (float)	
range:	[1.9]	units: 1
unique values:		coded missing: 583 / 642
uquo va_uoo.		
tabulation:	Freq. Value	
	25 1	
	8 2	
	4 3	
	4 4	
	5 5	
	2 6	
	3 7	
	8 9	

CSSCD FULL COHORT PATIENTS

F46MED3 ----- MEDICATION CODE type: numeric (float) range: [3,999] units: 1 values: 17 coded missing: 617 / 642 unique values: 17 tabulation: Freq. Value 1 3 2 28 1 59 1 99 1 137 2 190 1 196 1 209 1 230 2 249 1 311 1 316 1 370 372 1 420 6 480 1 999 F46MED3: 1. See Appendix D for medication codes. F46MDT3 ----- MEDICATION DAYS TAKEN type: numeric (float) range: [1,8] units: 1 unique values: 6 coded missing: 623 / 642tabulation: Freq. Value 6 1 5 2 4 3 2 4 1 6 1 8

```
F46WGT ----- WEIGHT (KG)
             type: numeric (float)
             range: [4.99,81.65] units: .01
values: 289 coded missing: 247 / 642
       unique values: 289
             mean: 26.8823
           std. dev: 17.6306
        percentiles: 10% 25% 50% 75% 90% 9.6 13.7 21 33.5 58.06
F46WGT:
 1. Required only if age \leq 15 years.
F46LVRSZ ------ SIZE OF LIVER
            type: numeric (float)
            range: [0,18] units: 1 values: 18 coded missing: 50 / 642
       unique values: 18
         tabulation: Freq. Value
                    261 0
                     45 1
                     85 2
                     45 3
                     50 4
                     32
                         5
                     22 6
                     10 7
                     14 8
                      9 9
                      7 10
                      1 11
                      5 12
                      1 13
                      1 14
                      2 16
                      1 17
                      1 18
F46LVRTN ----- LIVER TENDERNESS
             type: numeric (float)
             label: F46LVRTN
             range: [1,2] units: 1
values: 2 coded missing: 11 / 642
       unique values: 2
         tabulation: Freq. Numeric Label
                        1 ABSENT
2 PRESENT
                    544
                     87
```

CSSCD FULL COHORT PATIENTS

F46SPLP ------ PALPABLE SPLEEN type: numeric (float) label: F46SPLP units: 1 coded missing: 4 / 642 range: [1,2] unique values: 2 tabulation: Freq. Numeric Label 418 1 NO 220 2 YES F46SPLTP ----- SPLEEN TIP PALPATED (CM) type: numeric (float) range: [0,20] units: 1 unique values: 16 coded missing: 427 / 642 tabulation: Freq. Value 2 0 12 1 23 2 35 3 26 4 30 5 23 6 16 7 17 8 10 9 11 10 3 11 2 12 3 13 1 14 1 20

#### F46SPLTP:

Required only if F46SPLP=2.

CSSCD FULL COHORT PATIENTS

F46SPLDI ----- SPLEEN CM FROM MIDLINE type: numeric (float) range: [0,13] units: 1 coded missing: 520 / 642 unique values: 14 tabulation: Freq. Value 7 0 2 1 19 2 21 3 15 4 12 5 18 6 7 7 4 8 2 9 9 10 2 11 3 12 1 13 F46SPLDI: Required only if F46SPLTP=2. F46SPLTN ------ SPLEEN TENDERNESS type: numeric (float) label: F46SPLTN range: [1,2] units: 1 unique values: 2 coded missing: 26 / 642 tabulation: Freq. Numeric Label 542 1 ABSENT 74 2 PRESENT F460PHYS ----- OTHER PHYSICAL FINDINGS type: numeric (float) label: F460PHYS range: [1,2] units: 1 coded missing: 39 / 642 unique values: 2 tabulation: Freq. Numeric Label 299 1 NO 304 2 YES

CSSCD FULL COHORT PATIENTS

F46CBCHB ------ CBC HB

type: numeric (float)

range: [1.7,13.3] units: .1 values: 76 coded missing: 6 / 642 unique values: 76

mean: 5.41525 std. dev: 1.50715

percentiles: 10% 25% 50% 75% 3.7 4.5 5.3 6.1 90%

7.2

F46CBCHC ----- CBC HCT

type: numeric (float)

range: [6.5,40.2] units: .1 unique values: 182 coded missing: 5 / 642

mean: 15.9719 std. dev: 4.66967

percentiles: 10% 25% 50% 75% 90% 10.5 13.1 15.5 18.2 21.6

F46CBCRB ----- CBC RBC

type: numeric (float)

units: .01

range: [.82,4.68] unique values: 215 coded missing: 50 / 642

mean: 1.88579 std. dev: .640183

percentiles: 10% 25% 50% 75% 90% 1.15 1.475 1.78 2.15 2.63

F46CBCWB ----- CBC WBC

type: numeric (float)

range: [1.7,97.8] units: .1

coded missing: 12 / 642 unique values: 281

mean: 17.4233 std. dev: 10.5754

percentiles: 10% 25% 50% 75% 90% 6.7 9.8 15.2 22.6 30.6 90%

F46CRCWR:

1. WBC should be uncorrected for nRBC's.

CSSCD FULL COHORT PATIENTS

F46CBCMV ----- CBC MCV

type: numeric (float)

range: [32,121] units: 1 values: 64 coded missing: 35 / 642 unique values: 64

mean: 87.7578 std. dev: 10.6369

percentiles: 10% 25% 50% 75% 75 82 88 94 90%

100

F46HJB ----- HOWELL JOLLY BODIES

type: numeric (float)

label: F46HJB

range: [1,2] units: 1

units: 1 coded missing: 204 / 642 unique values: 2

tabulation: Freq. Numeric Label

1 ABSENT 239 199 2 PRESENT

F46PRBC ----- POCKED RBC

type: numeric (float)

range: [0,20.4] units: .1 values: 25 coded missing: 586 / 642 unique values: 25

mean: 3.38571 std. dev: 5.32184

percentiles: 10% 25% 50% 0 0 .2 75% 90%

.2 5.55 13.2

F46DFPMN ----- DIFFERENTIAL PMN

type: numeric (float)

range: [0,90]

units: 1 coded missing: 58 / 642 unique values: 78

mean: 53.6404 std. dev: 17.5279

percentiles: 10% 25% 50% 75% 90% 29 43 55 67 75

CSSCD FULL COHORT PATIENTS

F46DFBND ------ DIFFERENTIAL BANDS

type: numeric (float)

range: [0,80] units: 1 coded missing: 115 / 642 unique values: 34

mean: 5.00759 std. dev: 7.75332

percentiles: 10% 25% 50% 75% 90%

0 0 3 6 12

F46DFEOS ----- DIFFERENTIAL EOSINOPHILS

type: numeric (float)

range: [0,19] units: 1 values: 17 coded missing: 74 / 642 unique values: 17

mean: 1.69014 std. dev: 2.57565

percentiles: 10% 25% 50% 75% 90% 0 0 1 2 5

F46DFBAS ----- DIFFERENTIAL BASOPHILS

type: numeric (float)

range: [0,27] units: 1 values: 11 coded missing: 86 / 642 unique values: 11

mean: .534173 std. dev: 1.785

percentiles: 10% 25% 50% 75% 90% 0 0 1 10 0 0 1

F46DFLYM ----- DIFFERENTIAL LYMPHOCYTES

type: numeric (float)

range: [0,88] units: 1

coded missing: 57 / 642 unique values: 79

mean: 31.6889 std. dev: 16.6409

percentiles: 10% 25% 50% 75% 13 19 30 41 90%

56

CSSCD FULL COHORT PATIENTS

F46DFMON ----- DIFFERENTIAL MONOCYTES

type: numeric (float)

range: [0,31] units: 1 values: 27 coded missing: 61 / 642 unique values: 27

mean: 6.51807 std. dev: 4.93912

percentiles: 10% 25% 50% 75% 90%

1 3 6 9 13

F46DFATC ----- DIFFERENTIAL ATYPICAL CELLS

type: numeric (float)

range: [0,16] units: 1 values: 14 coded missing: 92 / 642 unique values: 14

mean: .716364 std. dev: 1.92375

percentiles: 10% 25% 50% 75% 90%

0 0 0 0 2

F46DFMM ------ DIFFERENTIAL METAMYELOCTYES | MYELOCYTES

type: numeric (float)

range: [0,15] units.

coded missing: 93 / 642 unique values: 10

mean: .484517 std. dev: 1.53613

percentiles:  $10\% \qquad 25\% \qquad 50\% \qquad 75\% \qquad 90\% \\ 0 \qquad 0 \qquad 0 \qquad 0 \qquad 2$ 

0 0 0 0

F46NRB ----- NUCLEATED RED BLOOD CELLS

type: numeric (float)

range: [0,99] units: 1

coded missing: 85 / 642 unique values: 67

mean: 11.3932 std. dev: 21.9369

percentiles: 10% 25% 50% 75% 0 0 2 10 90%

38

CSSCD FULL COHORT PATIENTS

F46PLATE ------ PLATELETS

type: numeric (float)

range: [17,1186] units: 1 coded missing: 123 / 642 unique values: 330

mean: 294.461 std. dev: 184.021

10% 25% 50% percentiles: 75% 90%

158 100 251 399 540

F46RETIC ------ RETICULOCYTES

type: numeric (float)

range: [0,57.4] units: .1 values: 247 coded missing: 46 / 642 unique values: 247

mean: 11.9185 std. dev: 11.1

percentiles: 10% 25% 50% 75% 90% 3 1.95 10 18.6 28

F46FOLIC ------ FOLIC ACID

type: numeric (float)

units: .01

range: [0,9.99] unique values: 17 coded missing: 624 / 642

mean: 5.84 std. dev: 2.85886

 
 10%
 25%
 50%
 75%

 1.23
 4.8
 6.25
 7.2
 percentiles: 90%

7.2 9.9

#### F46F0LIC:

1. Required only if reticulocytes are decreased or there are signs of marrow recovery (DIAGNOSIS: Aplastic Crisis).

CSSCD FULL COHORT PATIENTS

F46TIBC ----- TIBC type: numeric (float) units: 1 range: [72,654] units: 1 coded missing: 594 / 642 unique values: 39 mean: 239.917 std. dev: 91.09 percentiles: 10% 25% 50% 75% 90% 156 190 225 330 284.5 F46TIBC: 1. Required only if reticulocytes are decreased or there are signs of marrow recovery (DIAGNOSIS: Aplastic Crisis). F46FE ------ FE type: numeric (float) units: 1 coded missing: 579 / 642 range: [18,340] unique values: 55 mean: 128.746 std. dev: 88.6608 percentiles: 10% 25% 50% 75% 90% 35 51 93 203 253 F46FE: 1. Required only if reticulocytes are decreased or there are signs of marrow recovery (DIAGNOSIS: Aplastic Crisis). F46FERR ----- FERRITIN type: numeric (float)

range: [7,18026]

units: 1 coded missing: 593 / 642 unique values: 48

mean: 1557.14 std. dev: 2791.24

10% percentiles: 25% 50% 75% 90% 708 65 290 1670 3810

#### F46FERR:

1. Required only if reticulocytes are decreased or there are signs of marrow recovery (DIAGNOSIS: Aplastic Crisis).

CSSCD FULL COHORT PATIENTS

F46DBLRB ----- DIRECT BILIRUBIN

type: numeric (float)

range: [0,33.1] units: .1 coded missing: 479 / 642 unique values: 61

mean: 2.67239 std. dev: 4.28215

percentiles: 10% 25% 50% 75% 90% .2 .4 2.9 1.1 6.9

#### F46DBLRB:

1. Required only if reticulocytes are increased and there is a drop in hemoglobin (DIAGNOSIS: Hyperhemolytic Crisis).

F46BLRBN ----- INDIRECT BILIRUBIN

type: numeric (float)

units: .1

range: [.1,31.5] units: .1 coded missing: 510 / 642 unique values: 64

mean: 3.42045 std. dev: 3.83746

percentiles: 10% 25% 50% 75% 90%

.7 1.3 2.4 4.15

6.8

#### F46BLRBN:

1. Required only if reticulocytes are increased and there is a drop in hemoglobin (DIAGNOSIS: Hyperhemolytic Crisis).

F46COMBS ----- DIRECT COOMBS

type: numeric (float)

label: F46COMBS

range: [1,2] units: 1

unique values: 2 coded missing: 514 / 642

tabulation: Freq. Numeric Label

15 1 POSITIVE

2 NEGATIVE 113

#### F46COMBS:

1. Required only if reticulocytes are increased and there is a drop in hemoglobin (DIAGNOSIS: Hyperhemolytic Crisis).

CSSCD FULL COHORT PATIENTS

F46IGG ----- ANTI IGG type: numeric (float) label: F46IGG range: [1,2] units: 1 unique values: 2 coded missing: 539 / 642 tabulation: Freq. Numeric Label 1 POSITIVE 10 93 2 NEGATIVE F46IGG: 1. Required only if reticulocytes are increased and there is a drop in hemoglobin (DIAGNOSIS: Hyperhemolytic Crisis). F46ANTIC ----- ANTI C3 type: numeric (float) label: F46ANTIC range: [1,2] units.
2 coded missing: 542 / 642 unique values: 2 tabulation: Freq. Numeric Label 7 1 POSITIVE 93 2 NEGATIVE F46ANTIC: 1. Required only if reticulocytes are increased and there is a drop in hemoglobin (DIAGNOSIS: Hyperhemolytic Crisis). F46NECR ----- NECROSIS type: numeric (float) label: F46NECR range: [1,2] units: 1 unique values: 2 coded missing: 607 / 642 tabulation: Freq. Numeric Label 1 YES 1 34 2 NO

#### F46NECR:

Bone marrow aspiration required only if (1) there was a drop in Hb≥50%
 (2) Reticulocytes≤3% and (3) Nucleated RBC's≤5.

CSSCD FULL COHORT PATIENTS

F46CELL ----- ESTIMATED CELLULARITY type: numeric (float) range: [20,99] units: 1 coded missing: 622 / 642 unique values: 8 82 mean: std. dev: 19.8016 percentiles: 10% 25% 50% 75% 90% 80 55 90 97 99 F46CELL: 1. Bone marrow aspiration required only if (1) there was a drop in Hb≥50% (2) Reticulocytes≤3% and (3) Nucleated RBC's≤5. F46MYEY ----- MYELOID-ERYTHROID RATIO type: numeric (float) range: [1,99] units: 1 coded missing: 618 / 642 unique values: 13 mean: 15.625 std. dev: 23.4183 percentiles: 10% 25% 50% 75% 90% 1 5 8.5 13.5 50 F46MYEY: 1. Bone marrow aspiration required only if (1) there was a drop in Hb≥50% (2) Reticulocytes≤3% and (3) Nucleated RBC's≤5. F46IRON ----- IRON STORES type: numeric (float) label: F46IRON units: 1 coded missing: 618 / 642 range: [1,2] unique values: 2 tabulation: Freq. Numeric Label 1 PRESENT 23 2 ABSENT

#### F46TRON:

1. Bone marrow aspiration required only if (1) there was a drop in Hb≥50% (2) Reticulocytes≤3% and (3) Nucleated RBC's≤5.

1

CSSCD FULL COHORT PATIENTS

F46NMAT ----- NORMOBLASTIC MATURATION type: numeric (float) label: F46NMAT range: [1,2] units: 1 coded missing: 615 / 642 unique values: 2 tabulation: Freq. Numeric Label 9 1 NORMAL 18 2 ABNORMAL F46NMAT: 1. Bone marrow aspiration required only if (1) there was a drop in Hb≥50% (2) Reticulocytes≤3% and (3) Nucleated RBC's≤5. F46MMAT ----- MEGALOBLASTIC MATURATION type: numeric (float) label: F46MMAT range: [1,2] unit: ... coded missing: 612 / 642 unique values: 2 tabulation: Freq. Numeric Label 11 1 YES 19 2 NO F46MMAT: 1. Bone marrow aspiration required only if (1) there was a drop in Hb≥50% (2) Reticulocytes≤3% and (3) Nucleated RBC's≤5. F46LSC ----- LIVER-SPLEEN SCAN type: numeric (float) label: F46LSC range: [1,2] units: 1 unique values: 2 coded missing: 222 / 642 tabulation: Freq. Numeric Label 1 DONE 33

#### F46LSC:

1. Required if Splenic Sequestration.

387

2 NOT DONE

### CODEBOOK FOR CSSCD FORM 46 ACUTE ANEMIC EPISODE AND SPLENIC SEQUESTRATION FORM - PAGE 5

CSSCD FULL COHORT PATIENTS

F46HBS ------ HB \$ %

type: numeric (float)

range: [10,99] units: 1 values: 15 coded missing: 618 / 642 unique values: 15

mean: 67.2917 std. dev: 31.3417

percentiles: 10% 25% 50% 29 37.5 80 75% 90% 99 99

### F46HBS:

1. Required if Hb electrophoresis performed.

CSSCS FULL COHORT PATIENTS

F46FLOWS ----- NUMBER OF FLOW SHEETS type: numeric (float) range: [0,7] units.
values: 7 coded missing: 0 / 642 unique values: 7 tabulation: Freq. Value 75 0 394 1 131 2 30 3 9 4 2 5 F46FRM52 ----- IS THERE A FORM 52 ON THE DATABASE type: numeric (float) range: [0,48] units: 1 values: 10 coded missing: 0 / 642 unique values: 10 tabulation: Freq. Value 153 0 5 30 11 31 17 33 2 34 2 36 3 44 411 46 33 48 F46FRM52: 1. See Appendix N for list of CSSCD forms. F46DHOSP ----- NUMBER OF DAYS HOSPITALIZED type: numeric (float) range: [0,40] units: 1 coded missing: 61 / 642 unique values: 27 mean: 6.21343 std. dev: 4.58813 percentiles: 10% 25% 50% 75% 90% 2 3 5 8 12 5 8 2 3 12 \_dta: 1. Created 06/26/00.

A. <u>List of variables deleted</u> **F47DATE F47INIT F47NDATE F47LASTU F47LASTE F47ESTAT F47VDATE F47FCB F47DTE1-F47DTE6** 

CSSCS FULL COHORT PATIENTS

- B. List of variables modified NONE
- C. <u>List of variables modified with a name change</u> **NONE**
- D. Old name
- E. New name
- F. List of variables modified date to days since DOE
- G. Old name F47DATE
- H. New name **JF47DATE**
- I. <u>Collection Information</u>:

Form 47 (Acute Anemic Episode Flow Sheet) was completed each time a Form 46 was completed if a patient was hospitalized or seen daily as an outpatient for an acute anemic event.

The form collects daily and laboratory information from day 2 of hospitalization for the event through discharge. Each Form 47 contains 6 days of hospital information. Consequently, multiple From 47s can exist for a given event, dependent on length of stay or outpatient follow-up. Laboratory data are recorded every third hospital day (i.e., days 4, 7, 10, 13, etc.).

J. <u>Data Collection Period</u>: 03/79 – 12/86

Form 47 was used between 03/79 and 06/86 for all patients and continued to be used for patients < 6 months of age through 12/86.

K. Form Version Dates: 02/01/79, 03/01/79, 03/12/82

The codebook coincides with the most recent version of Form 47.

L. Files Used to Store Information:

SAS System File: R47.SD2

Format File: R47.FMT

M. Unique Record Identifiers: ANONID, F47DATE, F47SHEET

Records within the dataset are sorted by **ANONID**, **F47DATE**, **F47SHEET** (flow sheet number)

- N. Number of Observations (Patients) in SAS Dataset: 801 (417)
- O. Contents of SAS Dataset:
  - Alphabetical Listing of Variables: See pp. 642-643

CSSCS FULL COHORT PATIENTS

Listing of Variables by Position: See p. 644

### P. Notes About Selected Variables:

- **F47DTE1-F47DTE6** These date variables are four-digit integers composed of 2-digit month, 2-digit day of follow-up.
- F47CBWB, F47CBWB2 are the CBC White Blood Cell Count variables assumed to be "uncorrected" in relation to nucleated red blood cells (nRBCs).
- Q. Computed Variables: None

### R. Inter-Relationship with Other Datasets:

"Record 47" contains daily follow-up data for acute anemic events stored in **R46.SD2**. "Record 47" is linked to "Record 46" by **ANONID** and date patient sought care (if **F46DATE=F47DATE**).

The number of "Record 47s" which will link with any given "Record 46" is dependent on the length of the hospitalization or days followed as an outpatient. If a patient was hospitalized (or seen daily as an outpatient) for 7 days or less, then only one "Record 47" should be on the database for the event (**F47SHEET**=1). If a patient was hospitalized for 8-13 days, two "Record 47s" should be on the database, (**F47SHEET**=2 for days 8-13), etc.

The value for the variable **F46FLOWS** in **R46.SD2** is the number of Record 47s" in **R47.SD2** which link by date with the "Record 46." The value for the variable **F46DHOSP** in **R46.SD2** is the number of days hospitalized (i.e., the number of days information was collected on "Record 47s" which linked by date with the "Record 46").

ONTENTS OF SAS DATASET: R47.SD2

CSSCS FULL COHORT PATIENTS

DATA FROM CSSCD FORM 47 - ACUTE ANEMIC EPISODE FLOW SHEET VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION IN THE SAS DATASET AND ON FORM 47

The SAS System

16:42 Tuesday, January 30, 2007 3

### The CONTENTS Procedure

Data Set Name	OUT1.R47	Observations	801
Member Type	DATA	Variables	26
Engine	V9	Indexes	0
Created	15:48 Friday, January 19, 2007	Observation Length	208
Last Modified	15:48 Friday, January 19, 2007	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			

Data Representation WINDOWS

Encoding wlatin1 Western (Windows)

### Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	11
First Data Page	1
Max Obs per Page	78
Obs in First Data Page	59
Number of Data Set Repairs	0

File Name r47.sas7bdat 9.0000M0 Release Created Host Created XP\_PRO

### Alphabetic List of Variables and Attributes

	# Var	iable Type	e Le	en Label
1	ANONID	Char	8	ANONYMIZED ID #
16	F47CBHB	1 Num	8	CBC HB G DL
17	F47CBHB2	2 Num	8	CBC HB G DL
18	F47CBHC	1 Num	8	CBC HCT %
19	F47CBHC2	2 Num	8	CBC HCT %
20	F47CBWB	1 Num	8	CBC WBC X10NINTH L
21	F47CBWB2	2 Num	8	CBC WBC X10NINTH L
3	F47H0SP	Num	8	HOSPITALIZED OR OUTPATIENT
10	F47LVR1	Num	8	LIVER SIZE (CMS)
11	F47LVR2	Num	8	LIVER SIZE (CMS)
12	F47LVR3	Num	8	LIVER SIZE (CMS)
13	F47LVR4	Num	8	LIVER SIZE (CMS)
14	F47LVR5	Num	8	LIVER SIZE (CMS)
15	F47LVR6	Num	8	LIVER SIZE (CMS)
22	F47NRB1	Num	8	NUCLEATED RED BLOOD CELLS
23	F47NRB2	Num	8	NUCLEATED RED BLOOD CELLS
24	F47PLATE	E Num	8	PLATELET COUNT
25	F47RETIO	C Num	8	RETICULOCYTES
2	F47SHEE	Γ Num	8	SHEET NUMBER
4	F47SPLZ	1 Num	8	SPLEEN TIPS PALPATED (CM)

CSSCS FULL COHORT PATIENTS

5	F47SPLZ2	Num	8	SPLEEN TIPS PALPATED (CM)
6	F47SPLZ3	Num	8	SPLEEN TIPS PALPATED (CM)
7	F47SPLZ4	Num	8	SPLEEN TIPS PALPATED (CM)
8	F47SPLZ5	Num	8	SPLEEN TIPS PALPATED (CM)
9	F47SPLZ6	Num	8	SPLEEN TIPS PALPATED (CM)
26	JF47DATE	Num	8	DATE FIRST SOUGHT CARE - RECODE DAYS SINCE DOE

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

* R47.FMT contains value labels for numerical codes assigned to categorical*
* variables in the SAS dataset R47.SD2
***************************************
* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 04/25/99 11:49:29;
PROC FORMAT;
* FORMAT F47HOSP IS DEFINED FOR VARIABLE F47HOSP;
VALUE F47HOSP
1 = 'HOSPITALIZED'
2 = 'OUTPATIENT';
* FORMAT
F47HOSP F47HOSP.;
RUN; QUIT;

CSSCS FULL COHORT PATIENTS

F47SHEET ----- SHEET NUMBER type: numeric (float) range: [1,7] units.
values: 7 coded missing: 0 / 801 unique values: 7 tabulation: Freq. Value 569 1 173 2 42 3 12 4 3 5 1 6 1 7 F47VDATE ----- VERSION DATE DELETED type: numeric (int) label: datelab range: [6971,8106] units: 1 unique values: 3 coded missing: 0 / 801 tabulation: Freq. Numeric Label 125 6971 02/01/79 518 6999 03/01/79 158 8106 03/12/82 F47HOSP ----- HOSPITALIZED OR OUTPATIENT type: numeric (float) label: F47HOSP range: [1,2] units: 1
values: 2 coded missing: 12 / 801 unique values: 2 tabulation: Freq. Numeric Label 782 1 HOSPITALIZED 7 2 OUTPATIENT 7

F47SPL 71			SPLEEN	TIPS PALPATE	D (CM)	
1701221		numeric (fl		11.0 17.2.7.11	_D (0)	
	range:	[0,15]	units:	1		
	unique values:		coded missing:	102 / 801		
	tabulation:	Freq. Valu 450 0 11 1 34 2	e	tabulation:	25 12	8
		27 3			7	11
		22 4				12
		35 5				13
		30 6 14 7				14 15
F47SPLZ2		numeric (fl	SPLEEN oat)	TIPS PALPATE	ED (CM)	
		[0,13]	units:	1		
	unique values:	14	coded missing:	148 / 801		
	tabulation:	Freq. Valu 431 0 13 1 32 2 23 3 27 4 32 5 24 6	e	tabulation:	13 17 9 14 9 7	7 8
F47SPLZ3			SPLEEN	TIPS PALPATE	ED (CM)	
	type:	numeric (fl	oat)			
	range: unique values:		units: coded missing:			
	tabulation:	Freq. Valu 393 0 16 1 27 2 25 3 24 4 24 5 14 6	e	tabulation:	Freq. 11 14 6 12 9 6	7 8 9 10 11 12

E470DL 74		SPLEEN TIPS PALPATED (CM)
	numeric (float)	SPLEEN TIPS PALPATED (OM)
сурс.	Hamer to (Tioat)	
range:	[0,12]	units: 1
unique values:		coded missing: 333 / 801
·		,
tabulation:	Freq. Value	tabulation: Freq. Value
	324 0	6 7
	13 1	8 8
	24 2	4 9
	20 3	9 10
	15 4	6 11
	24 5	6 12
	9 6	
- 1-001		0015511 7700 04104750 (041)
		SPLEEN TIPS PALPATED (CM)
type:	numeric (float)	
nangai	[0 10]	units: 1
	[0,12]	units. I
unique values:	13	coded missing: 428 / 801
tabulation:	Freq. Value	tabulation: Freq. Value
	267 0	7 7
	7 1	7 8
	21 2	3 9
	13 3	7 10
	11 4	6 11
	15 5	2 12
	7 6	
F47SPI 76		SPLEEN TIPS PALPATED (CM)
	numeric (float)	or Elek Tiro Thermes (om)
ε, ροί	Hamor 10 (110at)	
range:	[0.12]	units: 1
unique values:		coded missing: 507 / 801
unique values.	10	00000 m1331ng. 307 / 001
tabulation:	Freq. Value	tabulation: Freq. Value
	209 0	3 7
	5 1	7 8
	14 2	2 9
	12 3	7 10
	9 4	5 11
	9 5	2 12
	10 6	2 12
	10 0	

				OOHORT TATIENTO			
F47LVR1					LIVER SIZE	(CMS)	
	type:	numeri	c (float)				
	range:	[0.18]		units:	1		
	unique values:			coded missing:			
	,			ŭ	,		
	tabulation:	Freq.	Value		tabulation:	Freq.	Value
		306	0			23	10
		39	1			11	11
		57				11	
		58				6	13
		42 41				8 5	14 15
		20				6	16
		14				1	17
		25				2	18
		20					
F47LVR2					LIVER SIZE	(CMS)	
	type:	numeri	c (float)				
	range:	[0 19]		units:	1		
	unique values:			coded missing:			
	anique varues.	13		ooded missing.	100 / 001		
	tabulation:	Freq.	Value		tabulation:	Freq.	Value
		290	0			24	10
		40	1			10	
		60				7	
		49				4	13
		37				9	14
		31 20				4 4	15 16
		11				1	17
		26				2	18
		19	9				
F47LVR3					LIVER SIZE	(CMS)	
	type:	numeri	c (float)				
	range:	[0,18]		units:	1		
	unique values:	19		coded missing:			
	unique varues.	13		coded missing.	223 / 001		
	tabulation:	Freq.	Value		tabulation:	Freq.	Value
		268	0			20	10
		28	1			8	11
		52				5	12
		53	3			4	13
		29	4			8	14
		23	5			2	15
		17				4	16 17
		10 26	7 8			1 2	17 18
		26 16	9			2	10
		10	9				

F47LVR4			c (float)		LIVER SIZE	(CMS)	
	range:			units:			
uni	ique values:	19		coded missing:	341 / 801		
	tabulation:	Freq.	Value		tabulation:	Freq.	Value
		210	0			14	10
		22	1			8	11
		34	2			4	12
		44	3			3	13
		26	4			4	14
		23	5			3	15
		14	6			5	16
		9	7			1	17
		20	8			1	18
		15	9				
- 471 VDE					LIVED CIZE	· (CMC)	
4/LVK5			c (float)		LIVER SIZE	(CMS)	
	range:	[0,18]		units:	1		
uni	ique values:			coded missing:	438 / 801		
	tabulation:	Freq.	Value		tabulation:	Freq.	Value
		171	0			12	9
		18	1			12	10
		21	2			8	11
		36				6	12
		21				1	13
		14				3	14
		9				2	15
		8				4	16
		15				2	18
: 47L VDC					L TVED 0175	. (0110)	
4/LVKO			c (float)		LIVER 51ZE	: (UNS)	
	range:	[0,20]		units:	1		
uni	ique values:			coded missing:	513 / 801		
	•			· ·		4	12
	tabulation:	Frea	Value				
	CADALACIONI					Enga	Value
	145414 (1511)	133			tabulation:	•	
	tubulu (10111	133 15	1		tabulation:	1	13
	casaracrom	133 15 20	1 2		tabulation:	1	13 14
		133 15 20 27	1 2 3		tabulation:	1 1 2	13 14 15
		133 15 20 27 16	1 2 3 4		tabulation:	1	13 14 15 16
		133 15 20 27 16 10	1 2 3 4 5		tabulation:	1 1 2	13 14 15 16 18
		133 15 20 27 16 10 7	1 2 3 4 5		tabulation:	1 1 2 4	13 14 15 16
		133 15 20 27 16 10 7	1 2 3 4 5 6 7		tabulation:	1 1 2 4 1	13 14 15 16 18
		133 15 20 27 16 10 7	1 2 3 4 5 6 7		tabulation:	1 1 2 4 1	13 14 15 16 18
		133 15 20 27 16 10 7	1 2 3 4 5 6 7 8		tabulation:	1 1 2 4 1	13 14 15 16 18
		133 15 20 27 16 10 7 6	1 2 3 4 5 6 7 8		tabulation:	1 1 2 4 1	13 14 15 16 18

### 7.6.0: Acute Anemic Events – Overview

F47CBHB1 ----- CBC HB G|DL type: numeric (float) range: [2.5,16] units: .1 values: 108 coded missing: 134 / 801 unique values: 108 mean: 8.08141 std. dev: 2.32235 10% 25% 50% 75% percentiles: 90% 6.4 7.9 11.2 5.3 9.6 F47CBHB2 ----- CBC HB G|DL type: numeric (float) range: [3,15.9] units. ...
values: 90 coded missing: 469 / 801 unique values: 90 mean: 8.36355 std. dev: 2.20505 percentiles: 10% 25% 50% 75% 90% 5.6 6.8 8.2 9.85 11.2 F47CBHC1 ----- CBC HCT % type: numeric (float) range: [8,47] units: .1 coded missing: 133 / 801 unique values: 256 mean: 23.9424 std. dev: 7.06104 percentiles: 10% 25% 50% 75% 90% 15.2 18.7 23.3 28.35 34 F47CBHC2 ----- CBC HCT % type: numeric (float)

range: [9,43.8] units: .1

coded missing: 469 / 801 unique values: 181

mean: 24.8497 std. dev: 6.59078

percentiles: 10% 25% 50% 75% 90%

16.8 19.95 24.15 29.5 33.8

### 7.6.0: Acute Anemic Events – Overview

F47CBWB1 ----- CBC WBC X10NINTH|L type: numeric (float) range: [2.5,59.5] units: .1 unique values: 228 coded missing: 267 / 801 mean: 14.3908 std. dev: 7.54783 25% 50% 75% 90% 9 13 17.8 24.4 10% percentiles: 90% 6.5 F47CBWB1: 1. WBC should be uncorrected for nRBC's. F47CBWB2 ----- CBC WBC X10NINTH|L type: numeric (float) range: [2.6,81.1] units: .1 unique values: 137 coded missing: 542 / 801mean: 14.1166 std. dev: 8.24284 50% percentiles: 10% 25% 75% 90% 7.2 9.1 12.1 16.9 21.6 F47CBWB2: 1. WBC should be uncorrected for nRBC's. F47NRB1 ----- NUCLEATED RED BLOOD CELLS type: numeric (float) range: [0,686] units: 1 values: 90 coded missing: 330 / 801 unique values: 90 mean: 26.4183 std. dev: 80.023 percentiles: 10% 25% 50% 75% 90% 0 0 2 12 64 F47NRB2 ----- NUCLEATED RED BLOOD CELLS type: numeric (float) units: 1 coded missing: 579 / 801 range: [0,664] unique values: 49 mean: 19.464 std. dev: 65.7415 percentiles: 10% 25% 50% 75% 90% 8 0 0

0

52

### 7.6.0: Acute Anemic Events – Overview

F47PLATE ------ PLATELET COUNT type: numeric (float) range: [43,1540] units: 1 values: 316 coded missing: 333 / 801 unique values: 316 mean: 363.489 std. dev: 228.34 10% 25% 50% percentiles: 75% 90% 115 184.5 315.5 480 666 F47PLATE: 1. Required only for the first 3 days. F47RETIC ----- RETICULOCYTES type: numeric (float) range: [0,71] units: .1 unique values: 203 coded missing: 255 / 801 mean: 10.6738 std. dev: 10.6113 10% percentiles: 25% 50% 75% 90% 2.1 7.8 16 25 .3 F47RETIC: 1. Required only for the first 3 days.

#### \_dta:

1. Run on 08/16/99.