

COOPERATIVE STUDY OF SICKLE CELL DISEASE

INTERIM STATUS REPORT FORM

ANONID  
INTID2

For the Limited Access Dataset, the following indications are used to indicate modifications of variables from the form

Deleted variable	Modified variable
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1. Person completing form (Name): \_\_\_\_\_ (Initials): \_\_\_\_\_ **INTEG**
2. CSSCD code number of person completing form: **INTCODE**
3. Date form completed (Month/Day/Year): \_\_\_\_\_ **INT\_DFC** \_\_\_\_/\_\_\_\_/\_\_\_\_

CHECK THE NO, YES OR DON'T KNOW BOX (when appropriate) FOR EACH OF THE FOLLOWING QUESTIONS:

4. Is the patient alive?  1. NO  2. YES  9. DK **INTALIV**
- IF NO TO ABOVE → 4.1 Date of death (Month, Day, Year) **INT\_DTH** \_\_\_\_/\_\_\_\_/\_\_\_\_

GO TO QUESTION #8  
COMPLETE CAUSE OF DEATH FORM

- IF DK TO ABOVE → 4.2 Year last known to be alive **INTLDATE**  1  9

5. Has the patient moved?  1. NO  2. YES  9. DK **INTMOVE**

5.1 Current Address/Telephone # Information:

5.1.A Do you have patient's current address?  1. NO  2. YES **INTADDR**

5.1.A.1 Current State of Residence: \_\_\_\_\_ **INTSTAT**

5.1.B Do you have patient's current telephone number?  1. NO  2. YES  3. N/A (no phone) **INTPHONE**

5.2 Will the patient continue to be followed at a CSSCD clinic/hospital?  1. NO  2. YES  9. DK **INTFUCL**

1. Clinic Name \_\_\_\_\_

2. Clinic Number

6. Is the patient refusing to participate?  1. NO  2. YES  9. DK **INTREFSL**

7. Has the patient transferred to another health care facility?  1. NO  2. YES  9. DK **INTTRNSF**

**IF YES TO ABOVE → 7.1. REASON: (CHECK ONLY ONE RESPONSE) INTTRRSN**

- 1. Parent/patient choice
- 2. Third party will not cover costs of care at CSSCD center
- 3. Other 7.2 SPECIFY:→ \_\_\_\_\_ **INTTROTH**

8. When was the last time the patient was seen in your clinic/hospital for any reason? **INT\_LSCL** \_\_\_\_/\_\_\_\_/\_\_\_\_

9. Since the last status report was completed on \_\_\_\_\_, has the patient been referred for any tests, consultations or diagnostic work-ups because of developmental delay, an intervening neurological event, abnormal MRI findings, abnormal neuropsychological evaluation, or abnormal neurologic exam ?

1. NO  2. YES  9. DK **INTREFER**

**IF YES TO ABOVE → Which tests or consultations? (CHECK NO OR YES BOX FOR EACH OF 9.1.A - 9.1.H)**

		1. NO	2. YES
9.1.A. Hearing evaluation/consultation	<b>INTHEAR</b>	<input type="checkbox"/>	<input type="checkbox"/>
9.1.B. Speech evaluation/consultation	<b>INTSPEEC</b>	<input type="checkbox"/>	<input type="checkbox"/>
9.1.C. Ophthalmology consultation - OTHER THAN VISUAL ACUITY EXAM/GLASSES	<b>INTOPTHM</b>	<input type="checkbox"/>	<input type="checkbox"/>
9.1.D. Developmental delay consultation	<b>INTDELAY</b>	<input type="checkbox"/>	<input type="checkbox"/>
9.1.E. Neurological consultation	<b>INTNEURO</b>	<input type="checkbox"/>	<input type="checkbox"/>
9.1.F. Additional neuroimaging studies	<b>INTIMAGE</b>	<input type="checkbox"/>	<input type="checkbox"/>
9.1.G. Obstructive sleep apnea	<b>INTOSA</b>	<input type="checkbox"/>	<input type="checkbox"/>
9.1.H. Other, specify : _____	<b>INTTSTSP</b> _____ <b>INTOTHE</b>	<input type="checkbox"/>	<input type="checkbox"/>

**\*\* NOTE: IF RESPONSE TO ANY OF 9.1.A - H IS YES, COMPLETE CONSULTATION COVER SHEET AND ATTACH REPORT TO COVER SHEET \*\***

10. Was patient seen for this annual exam?  1. NO  2. YES  3. N/A (semi-annual follow-up) **INTPE**

**IF NO TO ABOVE →** 10.1 Reason patient was not seen for annual exam (**CHECK ONLY ONE RESPONSE**): **INTPERS**

- 1. Patient moved outside of area.
- 2. Parent/guardian of patient is refusing because he/she is being followed at another health care facility within the area.
- 3. Parent/guardian of patient is refusing for other reason.

10.2 Specify Reason: **INTREFS** \_\_\_\_\_

- 4. Patient is in chronic care facility.
- 5. Patient was scheduled for visit, but missed appointment(s) because of illness.
- 6. Patient was scheduled for visit, but missed appointment(s) for other reason.
- 7. Patient did not move and is not lost-to-follow-up, but could not be contacted.
- 8. Patient lost (address and telephone number not known).

9. Patient died. → **COMPLETE DEATH FORM**

10. Other reason: 10.3 Specify Reason **INTOTHS** \_\_\_\_\_

**FILL IN THE BOXES OF QUESTION 11.1 - 11.5 USING THE FOLLOWING CODES:**

CODES:
1 - NOT REQUIRED IN PAST YEAR
2 - PATIENT UNABLE TO COOPERATE
3 - DONE
4 - SCHEDULED
5 - REFUSED
6 - MISSED SCHEDULED APPOINTMENTS
7 - NOT DONE FOR OTHER REASON

11. What is the status for each of the special studies listed below?

- 11.1 MRI of brain **INTMRI**  If, "not done for other reason," specify **INTMBRS** \_\_\_\_\_
- 11.2 Neuropsych tests **INTNP**  If, "not done for other reason," specify **INTNPRSN** \_\_\_\_\_
- 11.3 Psychosocial tests **INTPSY**  If, "not done for other reason," specify **INTPSYRS** \_\_\_\_\_
- 11.4 Pulmonary function tests **INTPFT**  If, "not done for other reason," specify **INTPFTRS** \_\_\_\_\_
- 11.5 Arterial blood gases **INTABG**  If, "not done for other reason," specify **INTABGRS** \_\_\_\_\_

Signature of Data Coordinator: \_\_\_\_\_

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

**QUESTION-BY-QUESTION SPECIFICATIONS FOR INTERIM STATUS REPORT FORM**

A. Collection information:

**CSSCD Phases 2 and 3**  
**1.5 Interim Status Report – Form INT**

**Form INT (Interim Status Report)** was used to collect information about the patient's current life status, study participation status, referrals for special evaluations, completion of routine and special study visit requirements. The form was completed every 6 months following entry into Phase 2 and at entry and at 6-month intervals following entry into Phase 3. For patients who participated in Phase 2 but did not enroll in Phase 3, an Interim Status Report was to be completed within two months following the date the patient was due to enter the Phase 3 study.

B. Data Collection Period: 03/90-09-98

Twenty-two forms were completed between 10/01/98 and 03/23/99.

C. Form Versions: B (03/06/90) – Phase 2

C (09/25/90) – Phase 2

E (10/01/91) – Phase 2

F (07/01/93) – Phase 2

H (06/23/94) – Phase 3

D. Files Used to Store Information:

SAS System File: **INT\_PUBN.SD2**

Format File: **INTN.FMT**

E. Unique Record Identifiers: **ANONID, INTID2**

Records within the dataset are sorted by **ANONID** and **INTID2**.

F. Number of Observations (Patients) in SAS Dataset: 4773 (467)

G. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 6-7
- Listing of Variables by Position: See pp. 8-9

H. Notes About Selected Variables: None

I. Computed Variables: None

J. Inter-Relationship With Other Datasets:

- Completion status variables for routine visit and special studies are stored in the **ROST2N3.SD2** SAS dataset (see Section 1.0)

- Data for completed routine visits were collected on

Form Abbreviation	SAS Dataset	See Section
HXP	<b><u>HXP_PUBN.SD2</u></b>	1.1
PEP	<b><u>PEP_PUBN.SD2</u></b>	1.2
NE	<b><u>NE_PUBN.SD2</u></b>	1.3
LAB	<b><u>LAB_PUBN.SD2</u></b>	1.4

- Data for completed special studies were collected on

Form Abbreviation	SAS Dataset	See Section
MRI	<b><u>MRI_PUBN.SD2</u></b>	2.1
MRA	<b><u>MRA_PUB.SD2</u></b>	2.2
NPC	<b><u>NPC_PUBN.SD2</u></b>	2.3
LISR	<b><u>LISRPUBN.SD2</u></b>	2.10
PFTP	<b><u>PFTPPUBN.SD2</u></b>	2.12

**CSSCD Phases 2 and 3**  
**1.5 Interim Status Report – Form INT**

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- Cause of death information was collected on

**Form Abbreviation**  
DEATH

**SAS Dataset**

**See Section**  
3.5

**DTH PUBN.SD2**

Question 1. Person completing form: The person completing the form enter his/her name on the line and initials in the three boxes to the right of the line.

Question 2. CSSCD code number of person completing form: The code number of the doctor or nurse completing the form/performing the exam is to be assigned by the Data Coordinator at each clinic.

Question 3. Date form completed: The date the form was completed should be entered in the MM/DD/YY date format (e.g. October 24, 1994 would be entered 10/24/94). The date the form is completed should be within two months of the due date for the report.

Question 4. Is the patient alive? Place a check mark in the appropriate (1. NO, 2. YES, or 9. DK (don't know)) box. If the response is 1. NO, enter the patient's date of death (Q. 4.1) and skip to Question 8. Be sure to complete a Cause of Death Form. If the response is 9. DK, enter the year the patient was last know to be alive (Q. 4.2).

Question 5. Has the patient moved? Place a check mark in the appropriate box (1. NO, 2. YES, or 9. DK (don't know)). If the response is 2. YES, complete items 5.1 and 5.2

Question 5.1.A. Do you have the patient's current address? Place a check mark in the appropriate response box (1. No or 2. Yes). If the response is 2. Yes, fill in the patient's current State of residence (Q.5.1.A.1). DO NOT fill in the boxes designated "OFFICE USE."

Question 5.1.B. Do you have the patient's current telephone number? Place a check mark in the appropriate response box (1. No, 2. Yes, or 3. N/A (no phone)).

Question 5.2. Will the patient continue to be followed at a CSSCD clinic/hospital? Place a check mark in the appropriate response box (1. No, 2. Yes, or 9. DK (don't know)). If the response to question 5.2 is 2. Yes, fill in the name and number of the CSSCD clinic the patient is being followed at in the spaces provided.

Question 6. Is the patient refusing to participate? Place a check mark in the appropriate response box (1. No, 2. Yes, or 9. DK (don't know)).

Question 7. Has the patient transferred to another health care facility? Place a check mark in the appropriate response box (1. NO, 2. YES, or 9. DK (don't know)). If the response is 2. YES, complete

**CSSCD Phases 2 and 3**  
**1.5: Interim Status Form – Form INT**

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question 7.1.

Question 7.1 REASON patient transferred to another health care facility. Check only ONE of the following response choices: 1. parent/patient choice, 2. third party will not cover costs of care at CSSCD center, *or* 3. other. If the response is 3. other, specify the reason in the space provided.

Question 8. When was the last time the patient was seen in your clinic/hospital for any reason? If the patient is being seen on the date that the form is being completed, then that is the date that should be entered here. The date should be entered in the MM/DD/YY date format (e.g., October24, 1994 would be entered 10/24/94).

Question 9. Since the last status report was completed [SUBSTITUTE DATE OF LAST STATUS REPORT FORM HERE], has the patient been referred for any tests, consultations or diagnostic work-ups because of developmental delay, an intervening neurological event, abnormal MRI findings, abnormal neuropsychological evaluation, or abnormal neurological exam? Review the patient's records carefully before responding to this question. Place a check mark in the appropriate response box (1. NO, 2. YES, *or* 9. DK (don't know)). If the response to question 9 is 2. YES, check the appropriate 1. NO or 2. YES box for EACH of the tests/consultations listed: 9.1.A. hearing, 9.1.B speech, 9.1.C. ophthalmology, 9.1 . D. developmental delay, 9.1 . E. neurological, 9.1 . F. additional neuroimaging studies, 9.1.G. obstructive sleep apnea, and 9.1.H. other. If the response to 9.1.H. "Other" is 2. YES, specify what the test/consultation was. For each consultation completed, a separate Consultation Report Cover Sheet should be completed and a copy of the corresponding test/consultation report should be stapled to it. The Consultation Report Cover Sheet and report should be forwarded to the SCC in the same package as the other forms for the study visit. DO NOT STAPLE OR CLIP THESE REPORTS TO THE INTERIM STATUS REPORT FORM. Be sure to cross out the patient's name on the reports and affix a CSSCD patient ID label to each report submitted.

Question 10. Was patient seen for this annual exam? A response to this question is REQUIRED IF the patient is due for an annual (including entry) visit. Place a check mark in the appropriate box (1. NO or 2. YES). If the response to question 10 is 1. NO, then question 10.1 MUST be completed.

Question 10.1 Reason patient was not seen for annual exam. Review all response choices before checking a response box. Check the ONE box which corresponds to the primary reason the patient was not seen for the visit. Response choices are: 1. Patient moved outside of area, 2. Parent/guardian is refusing because he/she is being followed at another health care facility within the area, 3. Parent/guardian of patient is refusing for other reason, 4. Patient is in chronic care facility, 5. Patient was scheduled for visit, but missed appointments because of illness, 6. Patient was scheduled for visit, but missed appointments for reasons other than illness, 7. Patient did not more and is not lost-to-follow-up, but could not be contacted, 8. Patient lost (address and telephone number unknown), 9. Patient died, 10. Other reason. If the reason is 3. Parent/guardian refusing for other reason, specify the reason in the

**CSSCD Phases 2 and 3**  
**1.5: Interim Status Form – Form INT**

space provided (Q. 10.2). If the reason is 10. Other reason, specify the reason in the space provided (Q. 10.3). If the reason the visit was not completed was because the patient died (response choice 9) prior to the date the visit was due, remember to complete a Cause of Death Form.

Question 11. What is the status for each of the special studies listed below? Fill in the appropriate code number for each of the studies listed using the code list located above and to the right of question 11. The studies listed are 11.1 MRI of brain, 11.2 Neuropsych tests 11.3 Psychosocial tests, 11.4 Pulmonary function tests, and 11.5 Arterial blood gases. the completion rating codes from which to choose are. 1. NOT REQUIRED IN PAST YEAR, 2. PATIENT UNABLE TO COOPERATE, 3. DONE, 4. SCHEDULED, 5. REFUSED, 6. MISSED SCHEDULE APPOINTMENTS, or 7. NOT DONE FOR OTHER REASON. If the response is 7. NOT DONE FOR OTHER REASON, the reason must be specified in the space, provided to the right of corresponding test.

**DATA MODIFICATIONS FOR LIMITED ACCESS DATA DISTRIBUTION**

A. The following variable has been deleted for privacy protection.

**INTCLINN INTMRIRS INTNPRSN INTPSYRS INTPFTRS INTABGRS**

B. The following variable has been calculated.

**INTPERSN**

C. The calculation for the above variable.

IF INTPERSN EQ 4 OR INTPERSN EQ 5 OR INTPERSN = 7  
 OR INTPERSN EQ 9 OR INTPERSN EQ 10 THEN INTPERSN = 10;

D. Calculated variable with distribution:

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The FREQ Procedure

101 REASON PT NOT SEEN FOR ANN EXAM

INTPERSN	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	51	20.00	51	20.00
2	43	16.86	94	36.86
3	24	9.41	118	46.27
6	78	30.59	196	76.86
8	26	10.20	222	87.06
10	33	12.94	255	100.00

Frequency Missing = 4518

CONTENTS OF SAS DATASET: INT\_PUBN.SD2

**CSSCD Phases 2 and 3**  
**1.5: Interim Status Form – Form INT**

DATA FROM CSSCD FORM INT - INTERIM STATUS REPORT FORM  
 VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION  
 IN THE SAS DATASET AND ON FORM INT  
 DATE VARIABLES HAVE BEEN REMOVED & CSSCD ID #S REPLACED W/ ANONYMIZED ID #

The SAS System 11:21 Monday, June 30, 2003 1

The CONTENTS Procedure

Data Set Name: IN.INT_PUBN	Observations:	4773
Member Type: DATA	Variables:	37
Engine: V6	Indexes:	0
Created: 11:36 Monday, June 30, 2003	Observation Length:	344
Last Modified: 11:36 Monday, June 30, 2003	Deleted Observations:	0
Protection:	Compressed:	NO
Data Set Type:	Sorted:	NO
Label:		

-----Engine/Host Dependent Information-----

Data Set Page Size:	16384
Number of Data Set Pages:	102
First Data Page:	1
Max Obs per Page:	47
Obs in First Data Page:	33
Number of Data Set Repairs:	0
File Name:	pub_sd2s\int_pubn.sd2
Release Created:	6.08.00
Host Created:	WIN

-----Alphabetic List of Variables and Attributes-----

#	Variable	Type	Len	Pos	Format	Informat	Label
36	ADD_BY	Char	8	328			INITIALS OF DATA ENTRY OPERATOR
1	ANONID	Char	8	0			ANONYMIZED ID #
33	INTABG	Num	8	310	2.	2.	115 STATUS OF ARTERIAL BLOOD GASES
9	INTADDR	Num	8	52	2.	2.	51A DO YOU HAVE PTS CURRENT ADDRESS
7	INTALIVE	Num	8	36	2.	2.	4 IS PATIENT ALIVE
4	INTBNO	Num	8	17	3.	3.	DATA ENTRY BATCH NUMBER
6	INTCODE	Num	8	28	3.	3.	2 CODE NO OF PERSON COMPLETING FORM
37	INTCONSF	Num	8	336	2.	2.	CONSULTATION FORM RECEIVED (PH2)
19	INTDELAY	Num	8	132	2.	2.	91D DEVELOPMENTAL DELAY CONSULTATION
5	INTFC	Char	3	25			1 PERSON COMPLETING FORM INITIALS
11	INTFUCL	Num	8	68	2.	2.	52 PT CONTIN FOLLOWED AT CSSCD CLINIC
16	INTHEAR	Num	8	108	2.	2.	91A HEARING EVALUATION/CONSULTATION
2	INTID2	Num	8	8	3.	3.	FOLLOW-UP IDENTIFIER
21	INTIMAGE	Num	8	148	2.	2.	91F ADDITIONAL NEUROIMAGING STUDIES
8	INTMOVE	Num	8	44	2.	2.	5 HAS PATIENT MOVED
29	INTMRI	Num	8	278	2.	2.	111 STATUS OF MRI OF BRAIN
20	INTNEURO	Num	8	140	2.	2.	91E NEUROLOGICAL CONSULTATION
30	INTNP	Num	8	286	2.	2.	112 STATUS OF NEUROPSYCH TESTS
18	INTOPTHM	Num	8	124	2.	2.	91C OPHTHALMOLOGY CONSULTATION
22	INTOSA	Num	8	156	2.	2.	91G OBSTRUCTIVE SLEEP APNEA
23	INTOTHER	Num	8	164	2.	2.	91H OTHER TEST/CONSULTATION
28	INTOTHS	Char	30	248			103 OTHER REASON SPECIFY
35	INTOVERS	Char	2	326			VERSION DATA TRANSCRIBED FROM
25	INTPE	Num	8	202	2.	2.	10 WAS PT SEEN FOR THIS ANNUAL EXAM
26	INTPERSN	Num	8	210	2.	2.	101 REASON PT NOT SEEN FOR ANN EXAM
32	INTPFT	Num	8	302	2.	2.	114 STATUS OF PULMONARY FUNCT TESTS
10	INTPHONE	Num	8	60	2.	2.	51B DO YOU HAVE PTS CURRENT PHONE #
31	INTPSY	Num	8	294	2.	2.	113 STATUS OF PSYCHOSOCIAL TESTS
15	INTREFER	Num	8	100	2.	2.	9 PT BEEN REFERRED FOR TESTS/CONSULTS



# CSSCD Phases 2 and 3

## 1.5: Interim Status Form – Form INT

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The SAS System

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The CONTENTS Procedure

-----Alphabetic List of Variables and Attributes-----

#	Variable	Type	Len	Pos	Format	Informat	Label
27	INTREFS	Char	30	218			102 PARENT REFUSE OTHR REASON SPECIFY
12	INTREFSL	Num	8	76	2.	2.	6 IS PATIENT REFUSING TO PARTICIPATE
17	INTSPEEC	Num	8	116	2.	2.	91B SPEECH EVALUATION/CONSULTATION
34	INTRNSC	Num	8	318	2.	2.	DATA TRANSCRIBED FROM OLDER VERSION
13	INTRNSF	Num	8	84	2.	2.	7 TRANSFERRED TO OTHR HLTHCARE FACIL
14	INTRRSN	Num	8	92	2.	2.	71 REASON TRANSFER TO OTHER FACILITY
24	INTTSTSP	Char	30	172			91H1 OTHER TEST/CONSULT SPECIFY
3	INTVERS	Char	1	16			FORM VERSION

**CODEBOOK FOR CSSCD FORM INT**  
**INTERIM STATUS REPORT FORM**  
CSSCD INFANT COHORT PATIENTS

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\*\*\*\*\*  
\* intn.fmt contains value labels for numerical codes assigned \*  
\* to categorical variables in the SAS dataset int\_pubn.sd2 \*  
\*\*\*\*\*;

PROC FORMAT;

VALUE ID2F 1='1-PH2 ENTRY'  
2='2-PH2 SEMI 1 FU'  
3='3-PH2 ANN 1 FU'  
4='4-PH2 SEMI 2 FU'  
5='5-PH2 ANN 2 FU'  
6='6-PH2 SEMI 3 FU'  
7='7-PH2 ANN 3 FU'  
8='8-PH2 SEMI 4 FU'  
9='9-PH2 ANN 4 FU'  
11='11-PH 3-ENTRY'  
12='12-PH 3 SEMI 1 FU'  
13='13-PH 3 ANN 1 FU'  
14='14-PH 3 SEMI 2 FU'  
15='15-PH 3 ANN 2 FU'  
16='16-PH 3 SEMI 3 FU'  
17='17-PH 3 ANN 3 FU'  
18='18-PH 3 SEMI 4 FU'  
19='19-PH 3 ANN 4 FU';

\*Format NO\_YES used for the following variables: INTALIVE INTMOVE  
INTFUCL INTREFSL INTTRNSF INTREFER;

VALUE NO\_YES 1='NO'  
2='YES'  
9='DONT KNOW';

VALUE INTPHONE 1='NO'  
2='YES'  
3='N/A NO PHONE';

VALUE INTPE 1='NO'  
2='YES'  
3='N/A SEMI ANNUAL';

VALUE INTTRSN 1='CHOICE'  
2='NO INS COVERAGE'  
3='OTHER';

\* Format NO\_YES2F used for the following variables: INTADDR INTHEAR  
INTSPEEC INTOPTHM INTDELAY INTNEURO INTIMAGE INTOSA INTOTHER INTTRNSC;

VALUE NO\_YES2F 1='NO'  
2='YES';

VALUE INTPERSN 1='MOVED OUTSIDE AREA'  
2='REFUSAL-FU ELSEWHERE'  
3='REFUSAL-OTHER REASON'  
6='MISSED APPT/OTH REAS'  
8='LOST-NO ADDRESS/PHONE'  
10='OTHER REASON';

**CODEBOOK FOR CSSCD FORM INT**  
**INTERIM STATUS REPORT FORM**  
CSSCD INFANT COHORT PATIENTS

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\*Format SPECTEST used for the following variables: INTMRI INTNP INTPSY  
INTPFT INTABG;

\*The SPECTEST variables will not have edits reissued;

VALUE SPECTEST 1='NOT REQUIRED'  
2='UNABLE TO COOPERATE'  
3='DONE'  
4='SCHEDULED'  
5='REFUSED'  
6='MISSED APPOINTMENTS'  
7='NOT DONE OTHER REAS';

VALUE INTCONSF 1='NO'  
2='YES';

VALUE INTDTHF 1='NO'  
2='YES';

FORMAT INTID2 ID2F. INTALIVE INTMOVE INTFUCL INTREFSL  
INTRRNSF INTREFER NO\_YES. INTPHONE INTPHONE. INTTRRSN INTTRRSN.  
INTADDR INTHEAR INTSPEEC INTOPTHM INTDELAY INTNEURO INTIMAGE INTOSA  
INTOTHER INTRRNSC NO\_YES2F. INTPE INTPE. INTPERSN INTPERSN. INTCONSF  
INTCONSF. INTMRI INTNP INTPSY INTPFT INTABG SPECTEST.;

RUN;  
QUIT;

CODEBOOK FOR CSSCD FORM INT  
INTERIM STATUS REPORT FORM - PAGE 1  
CSSCD INFANT COHORT PATIENTS

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INTID2 ----- FOLLOW-UP IDENTIFIER

type: numeric (float)

range: [2,19] units: 1  
unique values: 17 coded missing: 0 / 4773

tabulation: Freq. Value

451	2 PH2 SEMI 1 FU
424	3 PH2 ANN 1 FU
420	4 PH2 SEMI 2 FU
406	5 PH2 ANN 2 FU
4	6 PH2 SEMI 3 FU
392	7 PH2 ANN 3 FU
26	8 PH2 SEMI 4 FU
150	9 PH2 ANN 4 FU
438	11 PH 3-ENTRY
358	12 PH 3 SEMI 1 FU
345	13 PH 3 ANN 1 FU
346	14 PH 3 SEMI 2 FU
314	15 PH 3 ANN 2 FU
308	16 PH 3 SEMI 3 FU
366	17 PH 3 ANN 3 FU
6	18 PH 3 SEMI 4 FU
19	19 PH 3 ANN 4 FU

INTVERS ----- FORM VERSION

type: string (str1)

unique values: 5 coded missing: 0 / 4773

tabulation: Freq. Value

352	"B"
950	"C"
813	"E"
154	"F"
2504	"H"

INTALIVE ----- 4 IS PATIENT ALIVE

type: numeric (float)

range: [1,9] units: 1  
unique values: 3 coded missing: 0 / 4773

tabulation: Freq. Value

12	1 NO
4696	2 YES
65	9 DON'T KNOW

CODEBOOK FOR CSSCD FORM INT  
INTERIM STATUS REPORT FORM - PAGE 1  
CSSCD INFANT COHORT PATIENTS

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INTMOVE ----- 5 HAS PATIENT MOVED

type: numeric (float)

range: [1,9] units: 1  
unique values: 3 coded missing: 17 / 4773

tabulation:	Freq.	Value
	4259	1 NO
	455	2 YES
	42	9 DON'T KNOW

INTADDR ----- 51A DO YOU HAVE PTS CURRENT ADDRESS

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4318 / 4773

tabulation:	Freq.	Value
	47	1 NO
	408	2 YES

INTADDR:

1. Required only if INTMOVE = 2

**CODEBOOK FOR CSSCD FORM INT**  
**INTERIM STATUS REPORT FORM - PAGE 1**  
CSSCD INFANT COHORT PATIENTS

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INTPHONE ----- 51B DO YOU HAVE PTS CURRENT PHONE #

type: numeric (float)

range: [1,3]

units: 1

unique values: 3

coded missing: 4318 / 4773

tabulation:	Freq.	Value
	60	1 NO
	368	2 YES
	27	3 N/A NO PHONE

INTPHONE:

1. Required only if INTMOVE = 2

CODEBOOK FOR CSSCD FORM INT  
INTERIM STATUS REPORT FORM - PAGE 1  
CSSCD INFANT COHORT PATIENTS

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INTFUCL ----- 52 PT CONTIN FOLLOWED AT CSSCD CLINIC

type: numeric (float)

range: [1,9] units: 1  
unique values: 3 coded missing: 4317 / 4773

tabulation:	Freq.	Value
	71	1 NO
	359	2 YES
	26	9 DON'T KNOW

INTFUCL:

1. Required only if INTMOVE = 2

INTCLINN ----- 521 CLINIC TO BE FOLLOWED AT NAME **DELETED**

type: string (str2)

(names replaced with anonymized clinic letter code)

unique values: 15 coded missing: 4423 / 4773

tabulation:	Freq.	Value
	12	"AA"
	9	"D"
	26	"E"
	85	"F"
	2	"G"
	9	"H"
	49	"J"
	14	"M"
	8	"O"
	11	"P"
	6	"Q"
	2	"R"
	6	"U"
	62	"W"
	49	"Z"

INTCLINN:

1. Required only if INTFUCL = 2

INTREFSL ----- 6 IS PATIENT REFUSING TO PARTICIPATE

type: numeric (float)

range: [1,9] units: 1  
unique values: 3 coded missing: 20 / 4773

tabulation:	Freq.	Value
	4493	1 NO
	165	2 YES
	95	9 DON'T KNOW

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INTTRNSF ----- 7 TRANSFERRED TO OTHR HLTHCARE FACIL

type: numeric (float)

range: [1,9] units: 1  
unique values: 3 coded missing: 2311 / 4773

tabulation: Freq. Value  
2287 1 NO  
121 2 YES  
54 9 DON'T KNOW

INTTRNSF:

1. Required only if INTVERS = 'H'

INTTRRSN ----- 71 REASON TRANSFER TO OTHER FACILITY

type: numeric (float)

range: [1,3] units: 1  
unique values: 3 coded missing: 4653 / 4773

tabulation: Freq. Value  
44 1 CHOICE  
26 2 NO INS COVERAGE  
50 3 OTHER

INTTRRSN:

1. Required only if INTTRNSF = 2

INTREFER ----- 9 PT BEEN REFERRED FOR TESTS/CONSULTS

type: numeric (float)

range: [1,9] units: 1  
unique values: 3 coded missing: 12 / 4773

tabulation: Freq. Value  
4502 1 NO  
191 2 YES  
68 9 DON'T KNOW



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INTHEAR ----- 91A HEARING EVALUATION/CONSULTATION

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4583 / 4773

tabulation: Freq. Value  
167 1 NO  
23 2 YES

INTHEAR:

1. Required only if INTREFER = 2

INTSPEEC ----- 91B SPEECH EVALUATION/CONSULTATION

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4583 / 4773

tabulation: Freq. Value  
177 1 NO  
13 2 YES

INTSPEEC:

1. Required only if INTREFER = 2

INTOPTHM ----- 91C OPHTHALMOLOGY CONSULTATION

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4583 / 4773

tabulation: Freq. Value  
161 1 NO  
29 2 YES

INTOPTHM:

1. Required only if INTREFER = 2
2. Restricted to consultations for reasons other than visual acuity/glasses

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INTDELAY ----- 91D DEVELOPMENTAL DELAY CONSULTATION

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4583 / 4773

tabulation: Freq. Value  
178 1 NO  
12 2 YES

INTDELAY:

1. Required only if INTREFER = 2

INTNEURO ----- 91E NEUROLOGICAL CONSULTATION

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4593 / 4773

tabulation: Freq. Value  
110 1 NO  
70 2 YES

INTNEURO:

1. Required only if INTREFER = 2
2. Not required if INTVERS = 'B'

INTIMAGE ----- 91F ADDITIONAL NEUROIMAGING STUDIES

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4595 / 4773

tabulation: Freq. Value  
132 1 NO  
46 2 YES

INTIMAGE:

1. Required only if INTREFER = 2
2. Not required if INTVERS = 'B'

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INTOSA ----- 91G OBSTRUCTIVE SLEEP APNEA

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4681 / 4773

tabulation:	Freq.	Value
	87	1 NO
	5	2 YES

INTOSA:

1. Required only if INTREFER = 2 and INTVERS = 'H'

INTOTHER ----- 91H OTHER TEST/CONSULTATION

type: numeric (float)

range: [1,2] units: 1  
unique values: 2 coded missing: 4587 / 4773

tabulation:	Freq.	Value
	119	1 NO
	67	2 YES

INTOTHER:

1. Required only if INTREFER = 2
2. Not required if INTVERS = 'B'

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 CSSCD INFANT COHORT PATIENTS

INTTSTSP ----- 91H1 OTHER TEST/CONSULT SPECIFY

type: string (str30)

unique values: 60

coded missing: 0 / 4773

tabulation:

Freq.	Value	Freq.	Value
2	"A"	1	"ORTHOPEDIC-STIFF JOINTS & PAIN"
4706	"C"	1	"ORTHOPEDICS"
1	"ABD ULTRASOUND"	1	"PAIN MANAGEMENT"
1	"ARTERIOGRAM"	1	"PEDS SURGERY FOR GS EVALUATION"
1	"BEHAVIORAL SCIENCE FOR PICA"	1	"PHYSICAL THERAPY"
1	"BLADDER KIDNEY WORK-UP"	1	"PHYSICAL/OCCUPATIONAL THERAPY"
2	"CARDIOLOGY"	1	"PICA EVALUATION"
1	"DENTAL - FOR FILLINGS"	1	"PSYCH ADMISSION"
1	"DENTAL-CROWDING"	1	"PSYCH CONSULT-BEHAVIORAL/DEV"
1	"DEPRESSION EVALUATION"	1	"PSYCHIATRIC"
1	"ECHO/HOLTER MONITOR"	1	"PSYCHIATRIC EVALUATION"
2	"EEG"	2	"PSYCHOLOGICAL"
1	"ENDOCRINE"	1	"PSYCHOLOGICAL CONSULT"
1	"ENT FOR SNORING"	1	"PSYCHOLOGY"
1	"ENURESIS CLINIC FOR BEDWETTING"	1	"PULMONARY"
1	"ENURESIS EVALUATION"	1	"RECURRENT ABD PAIN"
1	"GYNE FOR BIRTH CONTROL"	1	"REHAB/OCCUPATIONAL THERAPY"
1	"HI RISK OB CLINIC"	1	"REHAB/REHAB URODYNAMICS"
1	"MRA"	2	"REHABILITATION"
1	"NEPHROLOGY"	1	"RENAL"
1	"NEUROLOGICAL"	1	"RENAL, PSYCH"
1	"NEUROLOGICAL EXAM-ABN MRI"	1	"REPEAT NEUROPSYCHOLOGICAL"
1	"NEUROPSYCH"	1	"SOCIAL SCIENCES-SCHOOL ABSENCE"
1	"NEUROPSYCH CONSULT"	1	"SPECIAL ED"
1	"NEUROPSYCH EXAM"	1	"STOP PROTOCOL"
1	"NEUROSURGERY"	2	"SURGERY"
1	"OCCUPATIONAL THERAPY"	2	"TCD"
1	"ORTHO & ABD. ULTRASOUND"	2	"TRANSCRANIAL DOPPLER"
1	"ORTHOPEDIC"	1	"ULTRASOUND OF GALLBLADDER"
1	"ORTHOPEDIC CONSULT"	1	"X-RAY FOR ABD PAIN"

INTTSTSP:

1. Required only if INTOTHER = 2

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INTPE ----- 10 WAS PT SEEN FOR THIS ANNUAL EXAM

type: numeric (float)

range: [1,3] units: 1  
unique values: 3 coded missing: 1308 / 4773

tabulation: Freq. Value  
257 1 NO  
2213 2 YES  
995 3 N/A SEMI-ANNUAL

INTPE:

1. Not required if INTVERS = 'B' or 'C'

INTPERSN ----- 101 REASON PT NOT SEEN FOR ANN EXAM **GROUPED**

type: numeric (float)

**SEE PAGE 7**

range: [1,10] units: 1  
unique values: 10 coded missing: 4518 / 4773

tabulation: Freq. Value  
51 1 MOVED OUTSIDE AREA  
43 2 REFUSAL-FU ELSEWHERE  
24 3 REFUSAL-OTHER REASON  
1 4 CHRON CARE FACILITY  
7 5 MISSED APPT/ILL  
78 6 MISSED APPT/OTHER REAS  
8 7 UNABLE TO CONTACT  
26 8 LOST-NO ADDRESS/PHONE  
3 9 DIED  
14 10 OTHER REASON

INTPERSN:

1. Required only if INTPE = 1



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INTMRI ----- 111 STATUS OF MRI OF BRAIN

type: numeric (float)

range: [1,7]

units: 1

unique values: 7

coded missing: 385 / 4773

tabulation: Freq. Value

1029	1 NOT REQUIRED
13	2 UNABLE TO COOPERATE
2015	3 DONE
546	4 SCHEDULED
187	5 REFUSED
164	6 MISSED APPOINTMENTS
434	7 NOT DONE OTH REAS

INTMRI:

1. Not required if INTVERS = 'B'

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INTMRIRS ----- 1111 MRI NOT DONE OTHER REASON SPECIFY **DELETED**

type: string (str25)

unique values: 83

coded missing: 0 / 4773

tabulation:

Freq.	Value	Freq.	Value
6	."	1	"PATIENT PANICKED"
1	"A"	1	"PATIENT PREGNANT"
4336	"C"	1	"PREGNANCY"
10	"< 6 YRS"	1	"PREGNANT"
1	"? TO BE SCHEDULED"	2	"PRIOR"
1	"BEHAVIOR PROBLEMS"	1	"PRIOR COMPLETION"
1	"CANNOT GET INTO CLINIC"	1	"PRIOR DONE"
1	"CHANGE IN GUARDIANSHIP"	9	"PRIOR TO"
1	"CLAUSTROPHOBIC"	2	"PRIOR TO LAST STUDY VISIT"
10	"COMPLETED"	1	"PRIOR TO LAST VISIT"
1	"DEATH"	1	"PT BECAME ILL IN CLINIC"
1	"DIDN'T KEEP SCHED APPTS."	1	"PT MISSED SCHEDULED APPTS"
1	"DISTANCE FROM CENTER"	2	"PT MOVED"
2	"FOLLOWED ELSEWHERE"	1	"PT MOVED,UNABLE TO LOCATE"
1	"HAD BEEN LTFU"	1	"PT PREGNANT"
1	"HAVEN'T SEEN PT IN 1 YR"	1	"PT. MOVED"
2	"HAVEN'T SEEN PT IN A YR"	1	"REACTION TO SEDATION"
1	"ILLNESS"	2	"REFUSED"
2	"LOST CONTACT"	6	"RESCHEDULED"
1	"LOST CONTACT DUE TO MOVE"	1	"S/P LOBECTOMY 2ND TO MVA"
1	"LOST TO FOLLOW-UP"	69	"SCHEDULED"
14	"LTFU"	1	"SCHEDULED 02/18/94"
2	"MENTALLY RETARDED"	1	"SCHEDULING"
27	"MISSED APPOINTMENT"	1	"SCHEDULING CONFLICT"
1	"MOM COULD NOT BE REACHED"	2	"SCHEDULING PROBLEM"
1	"MOM LEFT HOSPITAL"	1	"SCHEDX3-DIDN'T KEEP APPTS"
1	"MOM WON'T TAKE OFF WORK"	1	"SEDATION REACTION"
35	"MOVED"	53	"TO BE SCHEDULED"
1	"MOVED AND RETURNED"	1	"TOO YOUNG"
2	"MOVED OUT OF AREA"	1	"UNABLE TO BE TESTED"
1	"MOVED/LTFU"	8	"UNABLE TO CONTACT"
1	"MVA"	1	"UNABLE TO LOCATE"
1	"NEED TO SCHEDULE"	1	"UNABLE TO OBTAIN TRANSPRT"
1	"NO INSURANCE"	2	"UNABLE TO TOLERATE"
2	"NO SHOW"	1	"UNCOOPERATIVE"
5	"NONCOMPLIANT"	1	"UNKNOWN"
94	"NOT DUE"	1	"WAITING FOR MRA"
2	"NOT REQUIRED"	1	"WENT OUT OF STATE"
1	"PATIENT BECAME ILL"	3	"WILL NOT ENTER"
1	"PATIENT LOST"	10	"WILL SCHEDULE"
1	"PATIENT MOVED"		

INTMRIRS:

1. Required only if INTMRI =7



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INTNP ----- 112 STATUS OF NEUROPSYCH TESTS

type: numeric (float)

range: [1,7]

units: 1

unique values: 7

coded missing: 388 / 4773

tabulation: Freq. Value

1035	1 NOT REQUIRED
8	2 UNABLE TO COOPERATE
2035	3 DONE
483	4 SCHEDULED
179	5 REFUSED
170	6 MISSED APPOINTMENTS
475	7 NOT DONE OTHER REAS

INTNP:

1. Not required if INTVERS = 'B'

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 CSSCD INFANT COHORT PATIENTS

INTNPRSN ----- 1121 NEUROPSYCH NOT DONE SPECIFY **DELETED**

type: string (str25)

unique values: 89

coded missing: 0 / 4773

tabulation:

Freq.	Value	Freq.	Value
8	."	96	"NOT DUE"
1	"A"	2	"NOT REQUIRED"
4293	"C"	1	"PATIENT BECAME ILL"
1	"1"	1	"PATIENT LOST"
9	"< 6 YRS"	2	"PATIENT MOVED"
1	"< 6 YRS."	2	"PENDING"
1	"BEHAVIOR PROBLEMS"	1	"PREGNANT"
1	"CANNOT BE TESTED"	2	"PRIOR"
1	"CANNOT GET INTO CLINIC"	8	"PRIOR TO"
1	"CHANGE IN GUARDIANSHIP"	2	"PRIOR TO LAST STUDY VISIT"
9	"COMPLETED"	2	"PRIOR TO LAST VISIT"
1	"CONFLICT IN SCHEDULING"	1	"PT BECAME ILL IN CLINIC"
1	"DEATH"	1	"PT HAD STROKE"
1	"DID NOT COMPLETE TESTING"	1	"PT LEFT HOSPITAL/CLINIC"
1	"DIDN'T KEEP SCHED APPTS."	1	"PT MISSED SCHEDULED APPTS"
1	"DIFFICULTY W/ SCHEDULING"	2	"PT MOVED"
1	"DISTANCE FROM CENTER"	1	"PT MOVED,UNABLE TO LOCATE"
2	"FOLLOWED ELSEWHERE"	1	"PT PREGNANT"
1	"HAD BEEN LTFU"	1	"PT. MOVED"
1	"HAVEN'T SEEN PT IN 1 YR"	2	"REFUSED"
2	"HAVEN'T SEEN PT IN A YR"	1	"REFUSED MRI"
1	"ILLNESS"	1	"REFUSES TO COMPLETE"
2	"INCOMPLETE"	9	"RESCHEDULED"
1	"LEFT W/O COMPLETING"	1	"S/P LOBECTOMY 2ND TO MVA"
1	"LOST CONTACT"	59	"SCHEDULED"
1	"LOST CONTACT DUE TO MOVE"	1	"SCHEDULED 02/16/94"
1	"LOST TO FOLLOW-UP"	1	"SCHEDULED 1/91"
14	"LTFU"	1	"SCHEDULING"
1	"MENTAL RETARDATION"	2	"SCHEDULING CONFLICT"
1	"MENTALLY RETARDED"	3	"SCHEDULING PROBLEM"
36	"MISSED APPOINTMENT"	1	"SEVERE CVA-COULD NOT TEST"
1	"MISSED APPOINTMENT X2"	1	"STROKE"
1	"MISSED SEVERAL APPTS"	84	"TO BE SCHEDULED"
1	"MOM COULD NOT BE REACHED"	1	"TOO YOUNG"
1	"MOM WON'T TAKE OFF WORK"	1	"UNABLE TO BE TESTED"
34	"MOVED"	8	"UNABLE TO CONTACT"
1	"MOVED AND RETURNED"	1	"UNABLE TO DO"
2	"MOVED OUT OF AREA"	1	"UNABLE TO LOCATE"
1	"MOVED/LTFU"	1	"UNABLE TO OBTAIN TRANSPRT"
1	"MVA"	1	"WENT OUT OF STATE"
1	"NEED TO SCHEDULE"	3	"WILL NOT ENTER"
1	"NO INSURANCE"	1	"WILL RESCHEDULE"
2	"NO SHOW"	11	"WILL SCHEDULE"
5	"NONCOMPLIANT"		

INTNPRSN:

1. Required only if INTNP =7

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INTPSY ----- 113 STATUS OF PSYCHOSOCIAL TESTS

type: numeric (float)

range: [1,7]

units: 1

unique values: 7

coded missing: 2300 / 4773

tabulation: Freq. Value

1096	1 NOT REQUIRED
10	2 UNABLE TO COOPERATE
747	3 DONE
271	4 SCHEDULED
112	5 REFUSED
131	6 MISSED APPOINTMENTS
106	7 NOT DONE OTHER REAS

INTPSY:

1. Required only if INTVERS = 'H'

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INTPSYRS ----- 1131 PSYCHOSOCIAL NOT DONE SPECIFY **DELETED**

type: string (str25)

unique values: 56

coded missing: 0 / 4773

tabulation:

Freq.	Value	Freq.	Value
2	."	1	"NOT DUE"
1	"A"	1	"NOT REQ AT NEUROPSY TEST"
1	"B"	1	"NOT SCHEDULED"
4667	"C"	2	"NOT SCHEDULED W/ NP TESTS"
1	"CHANGE IN GUARDIANSHIP"	1	"PATIENT IN PAIN"
1	"DEATH"	1	"PATIENT MOVED"
1	"DID NOT RETURN FORMS"	1	"PREGNANT"
1	"FOLLOWED ELSEWHERE"	1	"PT DID NOT RETURN FORMS"
1	"FORGOT TO ADMINISTER"	1	"PT MISSED SCHEDULED APPTS"
4	"FORMS NOT AVAILABLE"	1	"PT MOVED"
4	"FORMS NOT DISTRIBUTED"	1	"PT MOVED,UNABLE TO LOCATE"
1	"FORMS NOT RECEIVED"	1	"PT PREGNANT"
1	"FORMS NOT RETURNED"	1	"PT UNABLE TO COMPLETE"
1	"HAVEN'T SEEN PT IN 1 YR"	1	"PT UNABLE TO COOPERATE"
2	"HAVEN'T SEEN PT IN A YR"	1	"REFUSED"
2	"INSUFFICIENT TIME"	1	"S/P LOBECTOMY 2ND TO MVA"
1	"INSUFFICIENT TIME, TBS"	1	"SEVERE CVA-COULD NOT TEST"
1	"LOST TO FOLLOW-UP"	1	"TBS"
6	"LTFU"	2	"TESTS NOT AVAILABLE"
3	"MATERIALS NOT AVAILABLE"	5	"TO BE SCHEDULED"
1	"MENTAL RETARDATION"	1	"UNABLE TO BE TESTED"
1	"MENTALLY RETARDED"	6	"UNABLE TO CONTACT"
1	"MENTALLY UNABLE TO DO"	1	"UNABLE TO CONTACT PT"
25	"MOVED"	1	"UNABLE TO PERFORM"
1	"MOVED AND RETURNED"	1	"UNABLE TO STAY TO COMPLET"
2	"MOVED OUT OF AREA"	1	"WENT OUT OF STATE"
1	"MVA"	1	"WILL NOT ENTER"
1	"NO TIME TO COMPLETE"		

INTPSYRS:

1. Required only if INTPSY =7

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INTPFT ----- 114 STATUS OF PULMONARY FUNCT TESTS

type: numeric (float)

range: [1,7]

units: 1

unique values: 7

coded missing: 428 / 4773

tabulation: Freq. Value

1160	1 NOT REQUIRED
17	2 UNABLE TO COOPERATE
1712	3 DONE
263	4 SCHEDULED
180	5 REFUSED
173	6 MISSED APPOINTEMENTS
840	7 NOT DONE OTHER REAS

INTPFT:

1. Not required if INTVERS = 'B'

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INTPFTRS ----- 1141 PULMONARY FUNCT NOT DONE SPECIFY **DELETED**

type: string (str25)

unique values: 121

coded missing: 0 / 4773

tabulation:

Freq.	Value	Freq.	Value
10	"."	1	"NO HEALTH INSURANCE"
2	"A"	1	"NO REASON"
3930	"C"	2	"NO SHOW"
9	"< 6 YRS"	2	"NONCOMPLIANT"
2	"ACUTE CHEST"	3	"NOT DUE"
1	"ACUTE CHEST 6/95"	1	"NOT INDICATED??"
1	"ACUTE CHEST ON DATE SCHED"	1	"NOT READY"
2	"ASTHMA"	1	"NOT READY TO RUN"
1	"ATTEMPTED-NOT COOPERATIVE"	15	"NOT SCHEDULED"
1	"BEHAVIOR PROBLEMS"	6	"NOT YET"
2	"BROKE APPOINTMENTS"	9	"NOT YET SCHEDULED"
1	"CANCELLED"	1	"PARENTS CONSIDERING"
1	"CANNOT GET INTO CLINIC"	1	"PATIENT BECAME ILL"
1	"CHANGE IN GUARDIANSHIP"	1	"PATIENT HAD STROKE"
1	"CLINIC CAN'T DO"	1	"PATIENT LOST"
1	"CONFLICT IN SCHEDULING"	2	"PATIENT MOVED"
1	"DEATH"	1	"PATIENT NON-COMPLIANT"
1	"DISTANCE FROM CENTER"	1	"PATIENT SICK"
1	"DONE OUTSIDE CLINIC"	1	"PATIENT TOO IMMATURE"
1	"DUE AFTER LAST VISIT"	8	"PENDING"
1	"ERROR IN SCHED/RESCHED 7/"	1	"PENDING APPT"
1	"FAILED APPTS"	3	"PENDING SCHEDULING"
2	"FOLLOWED ELSEWHERE"	4	"PER PROTOCOL"
1	"HAD BEEN LTFU"	5	"PNEUMONIA"
2	"HAVEN'T SEEN PT IN A YR"	1	"PREGNANCY"
2	"LOST CONTACT"	1	"PREGNANT"
1	"LOST CONTACT DUE TO MOVE"	2	"PRIOR TO LAST STUDY VISIT"
1	"LOST TO FOLLOW-UP"	1	"PRIOR TO LAST VISIT"
14	"LTFU"	1	"PT BECAME ILL IN CLINIC"
1	"MALFUNCTIONING MACHINE X2"	1	"PT DROOLS-COULD NOT TEST"
1	"MENTAL RETARDATION"	2	"PT MOVED"
1	"MENTALLY RETARDED"	1	"PT MOVED,UNABLE TO LOCATE"
1	"MISSED 3 APPTS"	1	"PT PREGNANT"
62	"MISSED APPOINTMENT"	1	"PT. NEVER KEPT APPTS."
1	"MISSED APPOINTMENT-RESCHED"	1	"RECURRENT CHEST EVENTS"
1	"MISSED APPT; WILL RESCHED"	3	"REFUSED PARTICIPATION"
1	"MISSED SEVERAL APPTS"	2	"RESCHEDULED"
1	"MOED"	1	"S/P LOBECTOMY 2ND TO MVA"
1	"MOM WON'T TAKE OFF WORK"	282	"SCHEDULED"
1	"MOTHER COULD NOT BE REACH"	7	"SCHEDULING"
1	"MOTHER NONCOMPLIANT"	2	"SCHEDULING CONFLICT"
1	"MOTHER WORKING"	5	"SCHEDULING PROBLEM"
37	"MOVED"	3	"SCHEDULING PROBLEMS"
1	"MOVED AND RETURNED"	1	"STROKE"
2	"MOVED OUT OF AREA"	1	"STUDY HASN'T STARTED"
1	"MOVED/LTFU"		
1	"MVA"		
1	"NEED TO SCHEDULE"		

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Freq.	Value	Freq.	Value
1	"TEST NOT STARTED"	1	"UNABLE TO GET RESULTS"
5	"TO BE RESCHEDULED"	1	"UNABLE TO OBTAIN TRANSPRT"
193	"TO BE SCHEDULED"	2	"UNABLE TO PERFORM"
4	"TOO IMMATURE"	1	"UNCOOPERATIVE"
2	"TOO YOUNG"	1	"UNCOOPERSTIVE; TOO NERVOU"
1	"TRANSPORTATION"	1	"UNKNOWN"
1	"UNABLE TO BE TESTED"	1	"WENT OUT OF STATE"
5	"UNABLE TO CONTACT"	1	"WILL BE DONE SOON"
1	"UNABLE TO CONTACT PT"	3	"WILL DO LATER"
3	"UNABLE TO DO"	2	"WILL DO WITH EXIT VISIT"
1	"UNABLE TO DO TEST"	3	"WILL NOT ENTER"
1	"UNABLE TO FOLLOW INSTRUC-"	4	"WILL RESCHEDULE"
		30	"WILL SCHEDULE"

INTPFTRS:

1. Required only if INTPFT =7

INTABG ----- 115 STATUS OF ARTERIAL BLOOD GASES

type: numeric (float)

range: [1,7]

units: 1

unique values: 7

coded missing: 2288 / 4773

tabulation:

Freq.	Value
663	1 NOT REQUIRED
23	2 UNABLE TO COOPERATE
1057	3 DONE
254	4 SCHEDULED
159	5 REFUSED
168	6 MISSED APPOINTMENTS
161	7 NOT DONE OTHER REAS

INTABG:

1. Response required only if INTVERS = 'H'

**CODEBOOK FOR CSSCD FORM INT**  
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 CSSCD INFANT COHORT PATIENTS

INTABGRS ----- 1151 ABG NOT DONE OTHER REASON SPECIFY **DELETED**

type: string (str25)

unique values: 76

coded missing: 0 / 4773

tabulation:

Freq.	Value	Freq.	Value
9	"."	1	"PATIENT TOO IMMATURE"
2	"B"	2	"PATIENT UNCOOPERATIVE"
4611	"C"	1	"PFT COULDN'T BE PERFORMED"
1	"ABG'S NOT DONE AT CENTER"	1	"PFT LAB WOULD NOT PERFORM"
3	"ACUTE CHEST"	3	"PNEUMONIA"
1	"ACUTE CHEST 6/95"	1	"PREGNANCY"
2	"ASTHMA"	1	"PREGNANT"
1	"ATTEMPTED-NOT COOPERATIVE"	1	"PT BECAME ILL IN CLINIC"
1	"CHANGE IN GUARDIANSHIP"	2	"PT MOVED"
1	"COULD NOT OBTAIN"	1	"PT MOVED,UNABLE TO LOCATE"
1	"DEATH"	1	"PT PREGNANT"
1	"DONE OUTSIDE CLINIC"	1	"RECURRENT CHEST EVENTS"
1	"FAILED AFTER MANY TRIES"	1	"REFUSED"
2	"FOLLOWED ELSEWHERE"	1	"S/P LOBECTOMY 2ND TO MVA"
1	"HAD BEEN LTFU"	2	"SCHEDULING PROBLEM"
1	"HAVEN'T SEEN PT IN 1 YR"	1	"SEVERAL"
2	"HAVEN'T SEEN PT IN A YR"	1	"STAFF + TIME PROBLEMS"
1	"LEFT BEFORE GETTING"	3	"TECH COULD NOT GET"
1	"LOST TO FOLLOW-UP"	1	"TECH UNABLE TO DRAW"
6	"LTFU"	1	"TECH UNABLE TO DRAW BLOOD"
1	"MADE SEVERAL ATTEMPTS"	9	"TO BE SCHEDULED"
1	"MALFUNCTIONING MACHINE X2"	1	"TRIED X 3, BLOOD CLOTTED"
1	"MENTAL RETARDATION"	1	"UNABLE AFTER MANY TRIES"
1	"MENTALLLY RETARDED"	1	"UNABLE TO BE TESTED"
28	"MOVED"	4	"UNABLE TO CONTACT"
1	"MOVED AND RETURNED"	1	"UNABLE TO CONTACT PT"
1	"MOVED OUT OF AREA"	1	"UNABLE TO DRAW"
1	"MOVED OUT OR AREA"	1	"UNABLE TO GET RESULTS"
1	"MOVED/LTFU"	1	"UNABLE TO LOCATE PATIENT"
1	"MVA"	2	"UNABLE TO OBTAIN"
14	"NOT DONE AT CENTER"	1	"UNABLE TO OBTAIN TRANSPRT"
8	"NOT PERFORMED AT CENTER"	2	"UNABLE TO PERFORM"
2	"PATIENT AGITATED"	1	"UNCOOPERATIVE"
1	"PATIENT BECAME ILL"	1	"UNKNOWN"
1	"PATIENT MOVED"	1	"UNSUCCESSFUL ATTEMPT"
1	"PATIENT NOT COOPERATIVE"	1	"WENT OUT OF STATE"
1	"PATIENT SICK"	3	"WILL NOT ENTER"

INTABGRS:

1. Required only if INTABG =7



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INTRNSC ----- DATA TRANSCRIBED FROM OLDER VERSION

type: numeric (float)  
range: [1,2] units: 1  
unique values: 2 coded missing: 2269 / 4773

tabulation: Freq. Value  
2410 1 NO  
94 2 YES

INTOVERS ----- VERSION DATA TRANSCRIBED FROM

type: string (str2)  
unique values: 4 coded missing: 0 / 4773

tabulation: Freq. Value  
4679 "C"  
16 "E"  
17 "F"  
61 "G"

INTOVERS:

1. Required only if INTRNSC = 2

INTCONSF ----- CONSULTATION FORM RECEIVED (PH2)

type: numeric (float)  
range: [1,2] units: 1  
unique values: 2 coded missing: 4692 / 4773

tabulation: Freq. Value  
54 1 NO  
27 2 YES

INTCONSF:

1. Required only if INTREFER = 2
2. Not required if INTVERS = 'H'

\_dta:

1. Created 03/14/2000