

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

DATA MODIFICATIONS FOR LIMITED ACCESS DATA DISTRIBUTION

A. The following variables have been deleted for privacy protection.

ADD_BY HXAPCS HXAPCYI HXBMTR HXCANC HXCANCC HXCANCT
HXCDIST HXCONPT HXCREFD HXCVAS HXCWAYI HXDISC HXEVS HSGF
HXEVHSGM HXGRREP HXHRAID HXMENIS HXMENIYI
HXMOTHT HXOSTEOS HXOSTEYI HXOTHPIN HXOTHPRT
HXOTHRXS HXOTHRXY HXOTHTW HXPNEUS HXPNEUYI HXPREG HXPREGN
HXPRIS HXPRIYI HXRELP HXSEIZS HXSEIZYI
HXSEPS HXSEPYI HXSPLSN HXSPLSS HXSPLSYI HXSURGC
HXSURGS HXSURGT HXSURGYI HXTRSP HXTRSP
HXEVHSM HXEVS HSF HXEVS HSS HXEVS HSB
HXEHAM HXEVS HAF HXEVS HAS HXEVS HAB
HXWHEEL HXWALKR HXLEGBR HCRTCH HXOTHW

B. The following variables have been calculated.

HXEVS HXEVA HXNOWALK

C. Calculations for the above variables.

```
IF HXEVS HSM = 2 OR HXEVS HSF = 2 OR HXEVS HSS = 2 OR HXEVS HSB = 2 THEN HXEVS = 2;  
IF HXEVS HSM = 1 AND HXEVS HSF = 1 AND HXEVS HSS = 1 AND HXEVS HSB = 1 THEN HXEVS = 1;  
*-----;  
IF HXEVS HAM = 2 OR HXEVS HAF = 2 OR HXEVS HAS = 2 OR HXEVS HAB = 2 THEN HXEVA = 2;  
IF HXEVS HAM = 1 AND HXEVS HAF = 1 AND HXEVS HAS = 1 AND HXEVS HAB = 1 THEN HXEVA = 1;  
*-----;  
IF HXWHEEL = 2 OR HXWALKR = 2 OR HXLEGBR = 2 OR HCRTCH = 2  
OR HXOTHW = 2 THEN HXNOWALK = 2;  
IF HXWHEEL = 1 AND HXWALKR = 1 AND HXLEGBR = 1 AND HCRTCH = 1  
AND HXOTHW = 1 THEN HXNOWALK = 1;
```

D. The following variables have been modified.

**HXTRANSN HXPCN HXPCYI HXOTHRXC HXOTHRXN HXHSENUM HXSIS HXBRO
HXOTHF1 HXOTHM1 HXOTHF2 HXOTHM2 HXHSETOT HXANINC HXNSCHDH HXPRINC
HXMASMT HXOTHPRO**

Other event ICD-9 code **HXOTHRXC** group algorithm:

```
IF HXOTHRXC EQ 282.62 THEN HXOTHRXC = 1;  
IF HXOTHRXC GE 9.1 AND HXOTHRXC LE 139.97 THEN HXOTHRXC = 2;  
IF HXOTHRXC GE 280 AND HXOTHRXC LE 282.61 THEN HXOTHRXC = 3;  
IF HXOTHRXC GE 282.63 AND HXOTHRXC LE 289.99 THEN HXOTHRXC = 3;  
IF HXOTHRXC GE 460 AND HXOTHRXC LE 466.99 THEN HXOTHRXC = 4;  
IF HXOTHRXC GE 493 AND HXOTHRXC LE 493.99 THEN HXOTHRXC = 5;  
IF HXOTHRXC EQ 780.6 THEN HXOTHRXC = 6;  
IF HXOTHRXC GE 800 AND HXOTHRXC LE 957.99 THEN HXOTHRXC = 7;  
IF HXOTHRXC GT 7 THEN HXOTHRXC = 8;
```

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

ICD-9 Code groups (definitions for **HXOTHRXC** groups).

- | | | |
|----|-----------------|--|
| 1. | 282.62 | Hb-S with mention of crisis |
| 2. | 1-139.97 | Infections and parasitic disease |
| 3. | 280.00-289.99 | Other diseases of blood and blood forming organs |
| | (exclude | |
| | 282.62) | |
| 4. | 460.00-466.99 | Acute respiratory infections |
| 5. | 493.00-493.99 | Asthma |
| 6. | 780.60 | Pyrexia of unknown origin |
| 7. | 800.00-957.99 | Injury |
| 8. | All other codes | Other |

E. Calculated variables with distributions:

The SAS System

11:00 Wednesday, June 11, 2003 5

The FREQ Procedure

FAMILY HISTORY OF STROKE

	HXEVHS	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	1	971	95.67	971	95.67
Yes	2	44	4.33	1015	100.00

Frequency Missing = 2091

FAMILY HSITORY OF ASTHMA

	HXEVHA	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	1	797	79.15	797	79.15
Yes	2	210	20.85	1007	100.00

Frequency Missing = 2099

ASSISTANCE NEEDED TO GET AROUND

	HXNOWALK	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	1	3040	98.61	3040	98.61
Yes	2	43	1.39	3083	100.00

Frequency Missing = 23

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

F. Modified variables with distributions:

82J TOTAL # UNIQUE EVENTS TRANSFUSION

HXTRANSN	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	85	39.91	85	39.91
2	31	14.55	116	54.46
3	15	7.04	131	61.50
4+	82	38.50	213	100.00

Frequency Missing = 2893

The FREQ Procedure

82L TOTAL # UNIQUE EVENTS PAIN CRISIS

HXPCN	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	197	45.29	197	45.29
2	96	22.07	293	67.36
3	48	11.03	341	78.39
4	28	6.44	369	84.83
5	20	4.60	389	89.43
6+	46	10.57	435	100.00

Frequency Missing = 2671

83L # PAIN CRISES AT YOUR INSTITUTION

HXPCYI	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	41	9.45	41	9.45
1	194	44.70	235	54.15
2	84	19.35	319	73.50
3	39	8.99	358	82.49
4	28	6.45	386	88.94
5	16	3.69	402	92.63
6+	32	7.37	434	100.00

Frequency Missing = 2672

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

OTHER EVENT ICD-9 CODE

HX0THRXC	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1.00	54	16.22	54	16.22
2.00	16	4.80	70	21.02
3.00	7	2.10	77	23.12
4.00	44	13.21	121	36.34
5.00	15	4.50	136	40.84
6.00	46	13.81	182	54.65
7.00	22	6.61	204	61.26
8.00	129	38.74	333	100.00

Frequency Missing = 2773

The FREQ Procedure

82M TOTAL # UNIQUE EVENTS OTHER

HX0THRXN	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	227	70.06	227	70.06
2	58	17.90	285	87.96
3	21	6.48	306	94.44
4+	18	5.56	324	100.00

Frequency Missing = 2782

19 # PEOPLE LIVE IN PTS HOUSE BESIDES PT

HXHSENUM	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	229	7.40	229	7.40
2	694	22.42	923	29.82
3	794	25.65	1717	55.48
4	562	18.16	2279	73.63
5	407	13.15	2686	86.79
6	189	6.11	2875	92.89
7	105	3.39	2980	96.28
8	70	2.26	3050	98.55
9	28	0.90	3078	99.45
10+	17	0.55	3095	100.00

Frequency Missing = 11

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

191C # SISTERS/STEPSISTERS

HXSIS	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	1417	45.74	1417	45.74
1	1125	36.31	2542	82.05
2	381	12.30	2923	94.35
3	141	4.55	3064	98.90
4+	34	1.10	3098	100.00

Frequency Missing = 8

The FREQ Procedure

191D # BROTHERS/STEPBROTHERS

HXBRO	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	1440	46.48	1440	46.48
1	1102	35.57	2542	82.05
2	374	12.07	2916	94.13
3	105	3.39	3021	97.51
4+	77	2.49	3098	100.00

Frequency Missing = 8

191E # OTHER FEMALE RELATIVES

HXOTHF1	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	2374	76.63	2374	76.63
1	477	15.40	2851	92.03
2	152	4.91	3003	96.93
3	59	1.90	3062	98.84
4+	36	1.16	3098	100.00

Frequency Missing = 8

191F # OTHER MALE RELATIVES

HXOTHM1	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	2645	85.38	2645	85.38
1	337	10.88	2982	96.26
2	74	2.39	3056	98.64
3	25	0.81	3081	99.45
4+	17	0.55	3098	100.00

Frequency Missing = 8

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

191G # OTHER UNRELATED FEMALES

HX0THF2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	3039	98.10	3039	98.10
1+	59	1.90	3098	100.00
Frequency Missing = 8				

The FREQ Procedure

191H # OTHER UNRELATED MALES

HX0THM2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	3020	97.48	3020	97.48
1+	78	2.52	3098	100.00
Frequency Missing = 8				

191I TOTAL NUMBER

HXHSETOT	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	229	7.40	229	7.40
2	694	22.42	923	29.82
3	794	25.65	1717	55.48
4	562	18.16	2279	73.63
5	407	13.15	2686	86.79
6	189	6.11	2875	92.89
7	105	3.39	2980	96.28
8	70	2.26	3050	98.55
9	28	0.90	3078	99.45
10+	17	0.55	3095	100.00
Frequency Missing = 11				

20 HOUSEHOLDS TOTAL ANNUAL INCOME

HXANINC	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	296	11.07	296	11.07
2	523	19.56	819	30.63
3	380	14.21	1199	44.84
4	270	10.10	1469	54.94
5	292	10.92	1761	65.86
6	292	10.92	2053	76.78
7	91	3.40	2144	80.18
8	42	1.57	2186	81.75
77	205	7.67	2391	89.42
99	283	10.58	2674	100.00
Frequency Missing = 432				

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The SAS System

11:00 Wednesday, June 11, 2003 10

The FREQ Procedure

DUE TO PTS HEALTH RELATED PROBS (PH2)

HXNSCHDH	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0	63	16.62	63	16.62
1	85	22.43	148	39.05
2	81	21.37	229	60.42
3	42	11.08	271	71.50
4	21	5.54	292	77.04
5	40	10.55	332	87.60
6	47	12.40	379	100.00

Frequency Missing = 2727

HOUSEHOLD PRIMARY SOURCE OF INCOME (PH2)

HXPRINC	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	28	2.04	28	2.04
2	517	37.60	545	39.64
8	673	48.95	1218	88.58
9	49	3.56	1267	92.15
11	38	2.76	1305	94.91
77	53	3.85	1358	98.76
99	17	1.24	1375	100.00

Frequency Missing = 1731

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

Data Set Name: OUT2.HXP_PUBN	Observations:	3106
Member Type: DATA	Variables:	169
Engine: V6	Indexes:	0
Created: 16:58 Monday, April 12, 2004	Observation Length:	1549
Last Modified: 16:58 Monday, April 12, 2004	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:	312
First Data Page:	2
Max Obs per Page:	10
Obs in First Data Page:	7
Number of Data Set Repairs:	0
File Name:	hxp_pubn.sd2
Release Created:	6.08.00
Host Created:	WIN

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

#	Variable	Type	Len	Pos	Format	Informat	Label
4	ANONID	Char	8	24			ANONYMIZED ID #
115	HXADD	Num	8	1024	2.	2.	251M PT CARRY DX OF ATTENTION DEFICIT
85	HXANINC	Num	8	716	2.	2.	20 HOUSEHOLDS TOTAL ANNUAL INCOME
37	HXAPC	Num	8	315	2.	2.	81D PT EXPERIENCE APLASTIC CRISIS
38	HXAPCN	Num	8	323	2.	2.	82D TOTAL # UNIQUE EVENTS APLAST CRISIS
98	HXASTH	Num	8	837	2.	2.	251A PT CARRY DX OF ASTHMA
6	HXBNO	Num	8	40	3.	3.	DATA ENTRY BATCH NUMBER
79	HXBRO	Num	8	668	2.	2.	191D # BROTHERS/STEPBROTHERS
125	HXBSTAT	Num	8	1104	2.	2.	30 IS PATIENT ON SPECIAL B STATUS
118	HXCDIS	Num	8	1048	2.	2.	251Q PT CARRY DX OF OTHER CHRON DISEASE
99	HXCHRTF	Num	8	845	2.	2.	251B PT CARRY DX OF CHRON HEART DISEASE
101	HXCHRTFC	Num	8	878	6.2	6.2	CHRONIC HEART DISEASE ICD-9 CODE
100	HXCHRTFT	Char	25	853			25B1 TYPE OF CHRON HEART DISEASE SPECIFY
102	HXCLIVF	Num	8	886	2.	2.	251C PT CARRY DX OF CHRON LIVER DISEASE
104	HXCLIVFC	Num	8	919	6.2	6.2	CHRONIC LIVER DISEASE ICD-9 CODE
103	HXCLIVFT	Char	25	894			25C1 TYPE OF CHRON LIVER DISEASE SPECIFY
89	HXCMPANH	Num	8	748	2.	2.	23B PT EVER EXPER ASEPTIC NECROSIS-HIP
90	HXCMPANS	Num	8	756	2.	2.	23C PT EVER EXPER ASEPTIC NECRO-SHOULDER
88	HXCMPLU	Num	8	740	2.	2.	23A PT EVER EXPERIENCED LEG ULCERS
91	HXCMPSCR	Num	8	764	2.	2.	23D PT EVER EXPER SC RETINOPATHY
24	HXCONP	Num	8	211	2.	2.	51G TAKING ORAL CONTRACEPTIVES
134	HXCONPC	Num	8	1170	6.	6.	ORAL CONTRACEPTIVES CODE (PH2)
25	HXCONPLV	Num	8	219	2.	2.	52G ORAL CNTRACPT START SINCE LAST VISIT
119	HXCORRL	Num	8	1056	2.	2.	26 DOES PATIENT WEAR CORRECTIVE LENSES
105	HXCREF	Num	8	927	2.	2.	251D PT CARRY DX OF CHRON RENAL DISEASE
107	HXCREFC	Num	8	960	6.2	6.2	CHRONIC RENAL DISEASE ICD-9 CODE
106	HXCREFFT	Char	25	935			25D1 TYPE OF CHRON RENAL DISEASE SPECIFY
92	HXCTRN	Num	8	772	2.	2.	24 IS PT CURRENTLY ON A CHRONIC TX PROG
94	HXCTRNCV	Num	8	788	2.	2.	242A INDICATION-STROKE

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

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

#	Variable	Type	Len	Pos	Format	Informat	Label
93	HXCTRNLV	Num	8	780	2.	2.	241 IS THIS NEW SINCE LAST STUDY VISIT
96	HXCTRNO	Num	8	804	2.	2.	242C INDICATION-OTHER
169	HXCTRNO	Num	8	1541	6.2	6.2	OTHER INDICATION FOR CHRON TX CODE (PH2)
97	HXCTRNOT	Char	25	812			242C1 OTHER REASON FOR TX SPECIFY
95	HXCTRPN	Num	8	796	2.	2.	242B INDICATION-RECURRENT PAIN EPISODES
31	HXCVA	Num	8	267	2.	2.	81A PT EXPERIENCE STROKE/TIA
32	HXCVAN	Num	8	275	2.	2.	82A TOTAL # UNIQUE EVENTS STROKE/TIA
109	HXDIAB	Num	8	976	2.	2.	251F PT CARRY DX OF DIABETES
67	HXDIFBR	Num	8	572	2.	2.	11 HAVE DIFFICULTY BREATHING WHEN ASLEEP
116	HXDYSL	Num	8	1032	2.	2.	251N PT CARRY DX OF DYSLEXIA
117	HXEPLL	Num	8	1040	2.	2.	251O PT CARRY DX OF ELEVATED BLOOD LEAD
63	HXENUR	Num	8	540	2.	2.	101 PT CURRENTLY HAVE PROBLEM W/ENURESIS
64	HXENURN	Num	8	548	2.	2.	1011 # NIGHTS/MONTH EXPERIENCES ENURESIS
2	HXEVHA	Num	8	8			FAMILY HSITORY OF ASTHMA
1	HXEVHS	Num	8	0			FAMILY HISTORY OF STROKE
77	HXFATHER	Num	8	652	2.	2.	191B # FATHER/STEPFATHER
121	HXFLU	Num	8	1072	2.	2.	291A PT EVER RCVD H INFLUENZA VACCINE
120	HXFLUYR	Num	8	1064	2.	2.	28 RCVD FLU VIRUS VACCINATION IN PAST YR
65	HXGETUP	Num	8	556	2.	2.	102 PT GETS UP DURING NIGHT TO URINATE
66	HXGETUPN	Num	8	564	2.	2.	1021 # NIGHTS/MONTH GETS UP TO URINATE
113	HXHIVP	Num	8	1008	2.	2.	251K PT CARRY DX OF HIV POSITIVITY
151	HXHLTH1	Num	8	1318	2.	2.	RATE PTS HEALTH TO OTHERS SAME AGE (PH2)
152	HXHLTH2	Num	8	1326	2.	2.	RATE PTS HLTH TO OTHERS W/SC (PH2)
153	HXHLTH3	Num	8	1334	2.	2.	RATE SELF HLTH TO OTHERS SAME AGE (PH2)
150	HXHLTHY	Num	8	1310	2.	2.	HLTHY ENOUGH TO DO THINGS WANTS TO (PH2)
75	HXHSENUM	Num	8	636	2.	2.	19 # PEOPLE LIVE IN PTS HOUSE BESIDES PT
84	HXHSETOT	Num	8	708	2.	2.	191I TOTAL NUMBER
5	HXID2	Num	8	32	3.	3.	FOLLOW-UP IDENTIFIER
108	HXIRNOV	Num	8	968	2.	2.	251E PT CARRY DX OF IRON OVERLOAD
114	HXLDIS	Num	8	1016	2.	2.	251L PT CARRY DX OF LEARNING DISABILITY
138	HXLIVS	Num	8	1202	2.	2.	PT TREATED FOR HEPATIC SEQUEST (PH2)
139	HXLIVSN	Num	8	1210	2.	2.	# TIMES SEEN FOR HEPATIC SEQUEST (PH2)
16	HXMASM	Num	8	113	2.	2.	51D TAKING ASTHMA MEDICATION
17	HXMASMLV	Num	8	121	2.	2.	52D ASTHMA MED STARTED SINCE LAST VISIT
18	HXMASMT	Char	25	129			53 SPECIFY ASTHMA MEDICATION
9	HXMEDS	Num	8	57	2.	2.	5 PT TAKING MEDS PRESCRIBED BY PHYSICIAN
43	HXMENI	Num	8	363	2.	2.	81G PT EXPERIENCE MENINGITIS
44	HXMENIN	Num	8	371	2.	2.	82G TOTAL # UNIQUE EVENTS MENINGITIS
13	HXMERYLV	Num	8	89	2.	2.	52B ERYTHROMYCN STARTED SINCE LAST VISIT
12	HXMERYTH	Num	8	81	2.	2.	51B TAKING ERYTHROMYCIN
14	HXMFOL	Num	8	97	2.	2.	51C TAKING FOLATE
15	HXMFOLLV	Num	8	105	2.	2.	52C FOLATE STARTED SINCE LAST VISIT
21	HXMIRC	Num	8	170	2.	2.	51F TAKING IRON CHELATORS
22	HXMIRCLV	Num	8	178	2.	2.	52F IRON CHELATOR START SINCE LAST VISIT
23	HXMIRCT	Char	25	186			54 SPECIFY IRON CHELATOR
130	HXMIRN	Num	8	1138	2.	2.	TAKING IRON (PH2)
131	HXMIRNLV	Num	8	1146	2.	2.	IRON STARTED SINCE LAST STDY VISIT (PH2)
26	HXMOTH	Num	8	227	2.	2.	51H TAKING OTHER MEDICATION
76	HXMOTHER	Num	8	644	2.	2.	191A # MOTHER/STEPMOTHER
27	HXMOTHLV	Num	8	235	2.	2.	52H OTHER MED STARTED SINCE LAST VISIT
10	HXMPEN	Num	8	65	2.	2.	51A TAKING PENICILLIN
11	HXMPENLV	Num	8	73	2.	2.	52A PCN STARTED SINCE LAST STUDY VISIT

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

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

#	Variable	Type	Len	Pos	Format	Informat	Label
70	HXMPER	Num	8	596	2.	2.	14 PT BEGUN PERIOD SINCE LAST STDY VISIT
19	HXMPPN	Num	8	154	2.	2.	51E TAKING ANALGESICS
20	HXMPPNLV	Num	8	162	2.	2.	52E ANALGESICS STARTED SINCE LAST VISIT
133	HXMPRLV	Num	8	1162	2.	2.	PROPS STARTED SINCE LAST STDY VISIT(PH2)
132	HXMPROPS	Num	8	1154	2.	2.	TAKING RANDOMIZED DRUG FOR PROPS (PH2)
3	HXNOWALK	Num	8	16			ASSISTANCE NEEDED TO GET AROUND
142	HXNSCHDH	Num	8	1234	2.	2.	# DUE TO PTS HEALTH RELATED PROBS (PH2)
145	HXNSCHDI	Num	8	1258	2.	2.	# DAYS ATTENDED SCHOOL ILL (PH2)
141	HXNSCHDM	Num	8	1226	2.	2.	# DIFFRENT WHOLE DAYS MISS SCHOOL (PH2)
155	HXOPRINC	Char	15	1350			OTHER SOURCE OF INCOME SPECIFY (PH2)
45	HXOSTEO	Num	8	379	2.	2.	81H PT EXPERIENCE OSTEOMYELITIS
46	HXOSTEON	Num	8	387	2.	2.	82H TOTAL # UNIQUE EVENTS OSTEOMYELITIS
135	HXOTHC	Num	8	1178	6.	6.	OTHER DRUG CODE (PH2)
80	HXOTHF1	Num	8	676	2.	2.	191E # OTHER FEMALE RELATIVES
82	HXOTHF2	Num	8	692	2.	2.	191G # OTHER UNRELATED FEMALES
81	HXOTHM1	Num	8	684	2.	2.	191F # OTHER MALE RELATIVES
83	HXOTHM2	Num	8	700	2.	2.	191H # OTHER UNRELATED MALES
29	HXOTHPRO	Num	8	251	2.	2.	63 PT PARTICIPATING IN OTHER STUDY
60	HXOTHRT	Char	25	499			87 OTHER EVENT SPECIFY
59	HXOTHRX	Num	8	491	2.	2.	81M PT EXPERIENCE OTHER
61	HXOTHRXC	Num	8	524	6.2	6.2	OTHER EVENT ICD-9 CODE
62	HXOTHRXN	Num	8	532	2.	2.	82M TOTAL # UNIQUE EVENTS OTHER
158	HXOUT1	Num	8	1393	2.	2.	OUTCOME TEST 1 (PH2)
162	HXOUT2	Num	8	1449	2.	2.	OUTCOME TEST 2 (PH2)
166	HXOUT3	Num	8	1505	2.	2.	OUTCOME TEST 3 (PH2)
128	HXOVERS	Char	2	1128			VERSION DATA TRANSCRIBED FROM
55	HXPC	Num	8	459	2.	2.	81L PT EXPERIENCE SICKLE PAIN CRISIS
129	HXPCARE	Num	8	1130	2.	2.	PERSON INTERVIEW PRIMARY CAREGIVER (PH2)
56	HXPCN	Num	8	467	2.	2.	82L TOTAL # UNIQUE EVENTS PAIN CRISIS
58	HXPCS	Num	8	483	2.	2.	85L WHERE SEEN FOR MOST RECENT CRISIS
57	HXPCYI	Num	8	475	2.	2.	83L # PAIN CRISES AT YOUR INSTITUTION
86	HXPST1	Num	8	724	2.	2.	21 EXTENT SCD AFFECTED PTS LIFE IN 6 MOS
87	HXPST2	Num	8	732	2.	2.	22 OVERALL DEGREE OF DISABILITY IN 6 MOS
8	HXPIN	Num	8	49	2.	2.	4 PERSON INTERVIEWED
41	HXPNEU	Num	8	347	2.	2.	81F PT EXPERIENCE PNEUMONIA/ACUTE CHEST
42	HXPNEUN	Num	8	355	2.	2.	82F TOTAL # UNIQUE EVENTS PNEUMONIA/ACS
47	HXPRI	Num	8	395	2.	2.	81I PT EXPERIENCE PRIAPISM
48	HXPRIN	Num	8	403	2.	2.	82I TOTAL # UNIQUE EVENTS PRIAPISM
154	HXPRINC	Num	8	1342	2.	2.	HOUSEHOLD PRIMARY SOURCE OF INCOME (PH2)
137	HXPROPS	Num	8	1194	2.	2.	IS PT PARTICIPATING IN PROPS2 (PH2)
136	HXRCHPRO	Num	8	1186	2.	2.	PARTICIP IN OTHR RESEARCH PROTOCOL (PH2)
147	HXREC	Num	8	1274	2.	2.	PT ABLE TO PARTIC IN RECREATION (PH2)
148	HXRECD	Num	8	1282	2.	2.	# DAYS UNABLE TO PARTIC PAST 2 WKS (PH2)
149	HXRECLM	Char	20	1290			REASON FOR THIS LIMITATION (PH2)
156	HXREF	Num	8	1365	2.	2.	REFERRED FOR TESTS SINCE LAST VST (PH2)
73	HXREPGR	Num	8	620	2.	2.	162 HAS PATIENT EVER REPEATED A GRADE
110	HXRHFEV	Num	8	984	2.	2.	251G PT CARRY DX OF RHEUMATIC FEVER
28	HXRPBUTY	Num	8	243	2.	2.	62 PT PARTICIPATING IN BUTYRATE STUDY
30	HXRX	Num	8	259	2.	2.	8 SINCE LAST VISIT PT SEEN FOR ANY EVENT
159	HXRX1	Num	8	1401	2.	2.	WAS TRTMNT RECOMMENDED AS RESULT (PH2)
163	HXRX2	Num	8	1457	2.	2.	WAS TRTMNT RECOMMENDED AS RESULT (PH2)
167	HXRX3	Num	8	1513	2.	2.	WAS TRTMNT RECOMMENDED AS RESULT (PH2)

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

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

#	Variable	Type	Len	Pos	Format	Informat	Label
160	HXRXT1	Char	20	1409			SPECIFY RECOMMENDED TREATMENT 1 (PH2)
164	HXRXT2	Char	20	1465			SPECIFY RECOMMENDED TREATMENT 2 (PH2)
168	HXRXT3	Char	20	1521			SPECIFY RECOMMENDED TREATMENT 3 (PH2)
71	HXSCH	Num	8	604	2.	2.	16 IS PATIENT ENROLLED IN SCHOOL
144	HXSCHDIL	Num	8	1250	2.	2.	PAST 2 WKS PT ATTEND SCHOOL ILL (PH2)
143	HXSCHDL	Num	8	1242	2.	2.	# DAYS ARRIVE LATE/LEAVE SCH EARLY (PH2)
140	HXSCHDM	Num	8	1218	2.	2.	PAST 2 WK PT MISS WHOLE DAY SCHOOL (PH2)
72	HXSCHLG	Num	8	612	2.	2.	161 LAST GRADE COMPLETED BY PATIENT
112	HXSEIZ	Num	8	1000	2.	2.	251J PT CARRY DX OF SEIZURE
34	HXSEIZN	Num	8	291	2.	2.	82B TOTAL # UNIQUE EVENTS SEIZURES
33	HXSEIZR	Num	8	283	2.	2.	81B PT EXPERIENCE SEIZURES
39	HXSEP	Num	8	331	2.	2.	81E PT EXPERIENCE SEPSIS
40	HXSEPN	Num	8	339	2.	2.	82E TOTAL # UNIQUE EVENTS SEPSIS
78	HXSIS	Num	8	660	2.	2.	191C # SISTERS/STEPSISTERS
68	HXSNORE	Num	8	580	2.	2.	12 DOES PATIENT SNORE
35	HXSPLS	Num	8	299	2.	2.	81C PT EXPERIENCE SPLENIC SEQUESTRATION
36	HXSPLSN	Num	8	307	2.	2.	82C TOTAL # UNIQUE EVENTS SPLEN SEQUEST
69	HXSTBR	Num	8	588	2.	2.	13 PT EVER STOP BREATHING WHILE SLEEPING
53	HXSURG	Num	8	443	2.	2.	81K PT HAVE SURGERY
54	HXSURGN	Num	8	451	2.	2.	82K TOTAL # UNIQUE EVENTS SURGERY
111	HXTB	Num	8	992	2.	2.	251H PT CARRY DX OF TUBERCULOSIS
146	HXTEASC	Num	8	1266	2.	2.	TEACHER KNOW PT HAS SICKLE CELL (PH2)
157	HXTEST1	Char	20	1373			ADDITIONAL TEST 1 (PH2)
161	HXTEST2	Char	20	1429			ADDITIONAL TEST 2 (PH2)
165	HXTEST3	Char	20	1485			ADDITIONAL TEST 3 (PH2)
49	HXTRANS	Num	8	411	2.	2.	81J PT HAVE TRANSFUSION
50	HXTRANSN	Num	8	419	2.	2.	82J TOTAL # UNIQUE EVENTS TRANSFUSION
52	HXTRANS	Num	8	435	2.	2.	85J WHERE SEEN FOR MOST RECENT TX
51	HXTRANSY	Num	8	427	2.	2.	83J # TRANSFUSIONS AT YOUR INSTITUTION
127	HXTRNSC	Num	8	1120	2.	2.	DATA TRANSCRIBED FROM OLDER VERSION
126	HXTRSL	Num	8	1112	2.	2.	31 TRANSLATOR NEEDED TO COMPLETE FORM
7	HXVERS	Char	1	48			FORM VERSION
123	HXVHEPB	Num	8	1088	2.	2.	291C PT EVER RCVD HEPATITIS B VACCINE
124	HXVMENIN	Num	8	1096	2.	2.	291D PT EVER RCVD MENINGOCOCCUS VACCINE
122	HXVPNE	Num	8	1080	2.	2.	292B PT EVER RCVD PNEUMOCOCCUS VACCINE
74	HXWALK	Num	8	628	2.	2.	17 PT ABLE TO WALK UP 5 STEPS W/OUT HELP

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

Data Set Name: OUT2.HXP_PUBN	Observations: 3106
Member Type: DATA	Variables: 169
Engine: V6	Indexes: 0
Created: 16:58 Monday, April 12, 2004	Observation Length: 1549
Last Modified: 16:58 Monday, April 12, 2004	Deleted Observations: 0

The CONTENTS Procedure

-----Variables Ordered by Position-----

#	Variable	Type	Len	Format	Informat	Label
1	HXEVS	Num	8			FAMILY HISTORY OF STROKE
2	HXEVA	Num	8			FAMILY HSITORY OF ASTHMA
3	HXNOWALK	Num	8			ASSISTANCE NEEDED TO GET AROUND
4	ANONID	Char	8			ANONYMIZED ID #
5	HXID2	Num	8	3.	3.	FOLLOW-UP IDENTIFIER
6	HXBNO	Num	8	3.	3.	DATA ENTRY BATCH NUMBER
7	HXVERS	Char	1			FORM VERSION
8	HXPIN	Num	8	2.	2.	4 PERSON INTERVIEWED
9	HXMEDS	Num	8	2.	2.	5 PT TAKING MEDS PRESCRIBED BY PHYSICIAN
10	HXMPEN	Num	8	2.	2.	51A TAKING PENICILLIN
11	HXMPENLV	Num	8	2.	2.	52A PCN STARTED SINCE LAST STUDY VISIT
12	HXMERYTH	Num	8	2.	2.	51B TAKING ERYTHROMYCIN
13	HXMERYLV	Num	8	2.	2.	52B ERYTHROMYCN STARTED SINCE LAST VISIT
14	HXMFOL	Num	8	2.	2.	51C TAKING FOLATE
15	HXMFOLLV	Num	8	2.	2.	52C FOLATE STARTED SINCE LAST VISIT
16	HXMASM	Num	8	2.	2.	51D TAKING ASTHMA MEDICATION
17	HXMASMLV	Num	8	2.	2.	52D ASTHMA MED STARTED SINCE LAST VISIT
18	HXMASMT	Char	25			53 SPECIFY ASTHMA MEDICATION
19	HXMPPN	Num	8	2.	2.	51E TAKING ANALGESICS
20	HXMPPNLV	Num	8	2.	2.	52E ANALGESICS STARTED SINCE LAST VISIT
21	HXMIRC	Num	8	2.	2.	51F TAKING IRON CHELATORS
22	HXMIRCLV	Num	8	2.	2.	52F IRON CHELATOR START SINCE LAST VISIT
23	HXMIRCT	Char	25			54 SPECIFY IRON CHELATOR
24	HXCONP	Num	8	2.	2.	51G TAKING ORAL CONTRACEPTIVES
25	HXCONPLV	Num	8	2.	2.	52G ORAL CNTRACPT START SINCE LAST VISIT
26	HXMOTH	Num	8	2.	2.	51H TAKING OTHER MEDICATION
27	HXMOTHLV	Num	8	2.	2.	52H OTHER MED STARTED SINCE LAST VISIT
28	HXRPBUTY	Num	8	2.	2.	62 PT PARTICIPATING IN BUTYRATE STUDY
29	HXOTHPRO	Num	8	2.	2.	63 PT PARTICIPATING IN OTHER STUDY
30	HRRX	Num	8	2.	2.	8 SINCE LAST VISIT PT SEEN FOR ANY EVENT
31	HXCVA	Num	8	2.	2.	81A PT EXPERIENCE STROKE/TIA
32	HXCVA	Num	8	2.	2.	82A TOTAL # UNIQUE EVENTS STROKE/TIA
33	HXSEIZR	Num	8	2.	2.	81B PT EXPERIENCE SEIZURES
34	HXSEIZN	Num	8	2.	2.	82B TOTAL # UNIQUE EVENTS SEIZURES
35	HXSPLS	Num	8	2.	2.	81C PT EXPERIENCE SPLENIC SEQUESTRATION
36	HXSPLSN	Num	8	2.	2.	82C TOTAL # UNIQUE EVENTS SPLEN SEQUEST
37	HXAPC	Num	8	2.	2.	81D PT EXPERIENCE APLASTIC CRISIS
38	HXAPCN	Num	8	2.	2.	82D TOTAL # UNIQUE EVENTS APLAST CRISIS
39	HXSEP	Num	8	2.	2.	81E PT EXPERIENCE SEPSIS
40	HXSEPN	Num	8	2.	2.	82E TOTAL # UNIQUE EVENTS SEPSIS
41	HXPNEU	Num	8	2.	2.	81F PT EXPERIENCE PNEUMONIA/ACUTE CHEST
42	HXPNEUN	Num	8	2.	2.	82F TOTAL # UNIQUE EVENTS PNEUMONIA/ACS
43	HXMENI	Num	8	2.	2.	81G PT EXPERIENCE MENINGITIS
44	HXMENIN	Num	8	2.	2.	82G TOTAL # UNIQUE EVENTS MENINGITIS
45	HXOSTEO	Num	8	2.	2.	81H PT EXPERIENCE OSTEOMYELITIS
46	HXOSTEON	Num	8	2.	2.	82H TOTAL # UNIQUE EVENTS OSTEOMYELITIS
47	HXPRI	Num	8	2.	2.	81I PT EXPERIENCE PRIAPISM
48	HXPRI	Num	8	2.	2.	82I TOTAL # UNIQUE EVENTS PRIAPISM
49	HXTRANS	Num	8	2.	2.	81J PT HAVE TRANSFUSION
50	HXTRANSN	Num	8	2.	2.	82J TOTAL # UNIQUE EVENTS TRANSFUSION
51	HXTRANSY	Num	8	2.	2.	83J # TRANSFUSIONS AT YOUR INSTITUTION
52	HXTRANS	Num	8	2.	2.	85J WHERE SEEN FOR MOST RECENT TX

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

-----Variables Ordered by Position-----

#	Variable	Type	Len	Format	Informat	Label
53	HXSURG	Num	8	2.	2.	81K PT HAVE SURGERY
54	HXSURGN	Num	8	2.	2.	82K TOTAL # UNIQUE EVENTS SURGERY
55	HXPC	Num	8	2.	2.	81L PT EXPERIENCE SICKLE PAIN CRISIS
56	HXPCN	Num	8	2.	2.	82L TOTAL # UNIQUE EVENTS PAIN CRISIS
57	HXPCYI	Num	8	2.	2.	83L # PAIN CRISES AT YOUR INSTITUTION
58	HXPCS	Num	8	2.	2.	85L WHERE SEEN FOR MOST RECENT CRISIS
59	HXOTHRX	Num	8	2.	2.	81M PT EXPERIENCE OTHER
60	HXOTHRT	Char	25			87 OTHER EVENT SPECIFY
61	HXOTHRXC	Num	8	6.2	6.2	OTHER EVENT ICD-9 CODE
62	HXOTHRXN	Num	8	2.	2.	82M TOTAL # UNIQUE EVENTS OTHER
63	HXENUR	Num	8	2.	2.	101 PT CURRENTLY HAVE PROBLEM W/ENURESIS
64	HXENURN	Num	8	2.	2.	1011 # NIGHTS/MONTH EXPERIENCES ENURESIS
65	HXGETUP	Num	8	2.	2.	102 PT GETS UP DURING NIGHT TO URINATE
66	HXGETUPN	Num	8	2.	2.	1021 # NIGHTS/MONTH GETS UP TO URINATE
67	HXDIFBR	Num	8	2.	2.	11 HAVE DIFFICULTY BREATHING WHEN ASLEEP
68	HXSNORE	Num	8	2.	2.	12 DOES PATIENT SNORE
69	HXSTBR	Num	8	2.	2.	13 PT EVER STOP BREATHING WHILE SLEEPING
70	HXMPER	Num	8	2.	2.	14 PT BEGUN PERIOD SINCE LAST STDY VISIT
71	HXSCH	Num	8	2.	2.	16 IS PATIENT ENROLLED IN SCHOOL
72	HXSCHLG	Num	8	2.	2.	161 LAST GRADE COMPLETED BY PATIENT
73	HXREPGR	Num	8	2.	2.	162 HAS PATIENT EVER REPEATED A GRADE
74	HXWALK	Num	8	2.	2.	17 PT ABLE TO WALK UP 5 STEPS W/OUT HELP
75	HXHSENUM	Num	8	2.	2.	19 # PEOPLE LIVE IN PTS HOUSE BESIDES PT
76	HXMOTHER	Num	8	2.	2.	191A # MOTHER/STEPMOTHER
77	HXFATHER	Num	8	2.	2.	191B # FATHER/STEPFATHER
78	HXSIS	Num	8	2.	2.	191C # SISTERS/STEPSISTERS
79	HXBRO	Num	8	2.	2.	191D # BROTHERS/STEPBROTHERS
80	HXOTHF1	Num	8	2.	2.	191E # OTHER FEMALE RELATIVES
81	HXOTHM1	Num	8	2.	2.	191F # OTHER MALE RELATIVES
82	HXOTHF2	Num	8	2.	2.	191G # OTHER UNRELATED FEMALES
83	HXOTHM2	Num	8	2.	2.	191H # OTHER UNRELATED MALES
84	HXHSETOT	Num	8	2.	2.	191I TOTAL NUMBER
85	HXANINC	Num	8	2.	2.	20 HOUSEHOLDS TOTAL ANNUAL INCOME
86	HXPST1	Num	8	2.	2.	21 EXTENT SCD AFFECTED PTS LIFE IN 6 MOS
87	HXPST2	Num	8	2.	2.	22 OVERALL DEGREE OF DISABILITY IN 6 MOS
88	HXCMPLU	Num	8	2.	2.	23A PT EVER EXPERIENCED LEG ULCERS
89	HXCMPANH	Num	8	2.	2.	23B PT EVER EXPER ASEPTIC NECROSIS-HIP
90	HXCMPANS	Num	8	2.	2.	23C PT EVER EXPER ASEPTIC NECRO-SHOULDER
91	HXCMPSCR	Num	8	2.	2.	23D PT EVER EXPER SC RETINOPATHY
92	HXCTRN	Num	8	2.	2.	24 IS PT CURRENTLY ON A CHRONIC TX PROG
93	HXCTRNLV	Num	8	2.	2.	241 IS THIS NEW SINCE LAST STUDY VISIT
94	HXCTRNCV	Num	8	2.	2.	242A INDICATION-STROKE
95	HXCTRNPV	Num	8	2.	2.	242B INDICATION-RECURRENT PAIN EPISODES
96	HXCTRNO	Num	8	2.	2.	242C INDICATION-OTHER
97	HXCTRNOT	Char	25			242C1 OTHER REASON FOR TX SPECIFY
98	HXASTH	Num	8	2.	2.	251A PT CARRY DX OF ASTHMA
99	HXCHRTF	Num	8	2.	2.	251B PT CARRY DX OF CHRON HEART DISEASE
100	HXCHRTFT	Char	25			25B1 TYPE OF CHRON HEART DISEASE SPECIFY
101	HXCHRTFC	Num	8	6.2	6.2	CHRONIC HEART DISEASE ICD-9 CODE
102	HXCLIVF	Num	8	2.	2.	251C PT CARRY DX OF CHRON LIVER DISEASE
103	HXCLIVFT	Char	25			25C1 TYPE OF CHRON LIVER DISEASE SPECIFY
104	HXCLIVFC	Num	8	6.2	6.2	CHRONIC LIVER DISEASE ICD-9 CODE

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

-----Variables Ordered by Position-----

#	Variable	Type	Len	Format	Informat	Label
105	HXCENRF	Num	8	2.	2.	251D PT CARRY DX OF CHRON RENAL DISEASE
106	HXCENRFT	Char	25			25D1 TYPE OF CHRON RENAL DISEASE SPECIFY
107	HXCENRFC	Num	8	6.2	6.2	CHRONIC RENAL DISEASE ICD-9 CODE
108	HXIRNOV	Num	8	2.	2.	251E PT CARRY DX OF IRON OVERLOAD
109	HXDIAB	Num	8	2.	2.	251F PT CARRY DX OF DIABETES
110	HXRHFVEV	Num	8	2.	2.	251G PT CARRY DX OF RHEUMATIC FEVER
111	HXTB	Num	8	2.	2.	251H PT CARRY DX OF TUBERCULOSIS
112	HXSEIZ	Num	8	2.	2.	251J PT CARRY DX OF SEIZURE
113	HXHIVP	Num	8	2.	2.	251K PT CARRY DX OF HIV POSITIVITY
114	HXLDIS	Num	8	2.	2.	251L PT CARRY DX OF LEARNING DISABILITY
115	HXADD	Num	8	2.	2.	251M PT CARRY DX OF ATTENTION DEFICIT
116	HXDYSL	Num	8	2.	2.	251N PT CARRY DX OF DYSLEXIA
117	HXEBLL	Num	8	2.	2.	251O PT CARRY DX OF ELEVATED BLOOD LEAD
118	HXCDIS	Num	8	2.	2.	251Q PT CARRY DX OF OTHER CHRON DISEASE
119	HXCORRL	Num	8	2.	2.	26 DOES PATIENT WEAR CORRECTIVE LENSES
120	HXFLUYR	Num	8	2.	2.	28 RCVD FLU VIRUS VACCINATION IN PAST YR
121	HXFLU	Num	8	2.	2.	291A PT EVER RCVD H INFLUENZA VACCINE
122	HXVPNE	Num	8	2.	2.	292B PT EVER RCVD PNEUMOCOCCUS VACCINE
123	HXVHEPB	Num	8	2.	2.	291C PT EVER RCVD HEPATITIS B VACCINE
124	HXVMENIN	Num	8	2.	2.	291D PT EVER RCVD MENINGOCOCCUS VACCINE
125	HXBSTAT	Num	8	2.	2.	30 IS PATIENT ON SPECIAL B STATUS
126	HXTRSL	Num	8	2.	2.	31 TRANSLATOR NEEDED TO COMPLETE FORM
127	HXTRNSC	Num	8	2.	2.	DATA TRANSCRIBED FROM OLDER VERSION
128	HXOVERS	Char	2			VERSION DATA TRANSCRIBED FROM
129	HXPCARE	Num	8	2.	2.	PERSON INTERVIEW PRIMARY CAREGIVER (PH2)
130	HXMIRN	Num	8	2.	2.	TAKING IRON (PH2)
131	HXMIRNLV	Num	8	2.	2.	IRON STARTED SINCE LAST STDY VISIT (PH2)
132	HXMPPROPS	Num	8	2.	2.	TAKING RANDOMIZED DRUG FOR PROPS (PH2)
133	HXMPLRV	Num	8	2.	2.	PROPS STARTED SINCE LAST STDY VISIT(PH2)
134	HXCONPC	Num	8	6.	6.	ORAL CONTRACEPTIVES CODE (PH2)
135	HXOTHC	Num	8	6.	6.	OTHER DRUG CODE (PH2)
136	HXRCHPRO	Num	8	2.	2.	PARTICIP IN OTHR RESEARCH PROTOCOL (PH2)
137	HXPROPS	Num	8	2.	2.	IS PT PARTICIPATING IN PROPS2 (PH2)
138	HXLIVS	Num	8	2.	2.	PT TREATED FOR HEPATIC SEQUEST (PH2)
139	HXLIVSN	Num	8	2.	2.	# TIMES SEEN FOR HEPATIC SEQUEST (PH2)
140	HXSCHDM	Num	8	2.	2.	PAST 2 WK PT MISS WHOLE DAY SCHOOL (PH2)
141	HXNSCHDM	Num	8	2.	2.	# DIFFRENT WHOLE DAYS MISS SCHOOL (PH2)
142	HXNSCHDH	Num	8	2.	2.	# DUE TO PTS HEALTH RELATED PROBS (PH2)
143	HXSCHDL	Num	8	2.	2.	# DAYS ARRIVE LATE/LEAVE SCH EARLY (PH2)
144	HXSCHDIL	Num	8	2.	2.	PAST 2 WKS PT ATTEND SCHOOL ILL (PH2)
145	HXNSCHDI	Num	8	2.	2.	# DAYS ATTENDED SCHOOL ILL (PH2)
146	HXTEASC	Num	8	2.	2.	TEACHER KNOW PT HAS SICKLE CELL (PH2)
147	HXREC	Num	8	2.	2.	PT ABLE TO PARTIC IN RECREATION (PH2)
148	HXRECD	Num	8	2.	2.	# DAYS UNABLE TO PARTIC PAST 2 WKS (PH2)
149	HXRECLM	Char	20			REASON FOR THIS LIMITATION (PH2)
150	HXHLTHY	Num	8	2.	2.	HLTHY ENOUGH TO DO THINGS WANTS TO (PH2)
151	HXHLTH1	Num	8	2.	2.	RATE PTS HEALTH TO OTHERS SAME AGE (PH2)
152	HXHLTH2	Num	8	2.	2.	RATE PTS HLTH TO OTHERS W/SC (PH2)
153	HXHLTH3	Num	8	2.	2.	RATE SELF HLTH TO OTHERS SAME AGE (PH2)
154	HXPRINC	Num	8	2.	2.	HOUSEHOLD PRIMARY SOURCE OF INCOME (PH2)
155	HXOPRINC	Char	15			OTHER SOURCE OF INCOME SPECIFY (PH2)
156	HXREF	Num	8	2.	2.	REFERRED FOR TESTS SINCE LAST VST (PH2)

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

The CONTENTS Procedure

-----Variables Ordered by Position-----

#	Variable	Type	Len	Format	Informat	Label
157	HXTEST1	Char	20			ADDITIONAL TEST 1 (PH2)
158	HXOUT1	Num	8	2.	2.	OUTCOME TEST 1 (PH2)
159	HXRXT1	Num	8	2.	2.	WAS TRTMENT RECOMMENDED AS RESULT (PH2)
160	HXRXT1	Char	20			SPECIFY RECOMMENDED TREATMENT 1 (PH2)
161	HXTEST2	Char	20			ADDITIONAL TEST 2 (PH2)
162	HXOUT2	Num	8	2.	2.	OUTCOME TEST 2 (PH2)
163	HXRXT2	Num	8	2.	2.	WAS TRTMENT RECOMMENDED AS RESULT (PH2)
164	HXRXT2	Char	20			SPECIFY RECOMMENDED TREATMENT 2 (PH2)
165	HXTEST3	Char	20			ADDITIONAL TEST 3 (PH2)
166	HXOUT3	Num	8	2.	2.	OUTCOME TEST 3 (PH2)
167	HXRXT3	Num	8	2.	2.	WAS TRTMENT RECOMMENDED AS RESULT (PH2)
168	HXRXT3	Char	20			SPECIFY RECOMMENDED TREATMENT 3 (PH2)
169	HXCTRNOC	Num	8	6.2	6.2	OTHER INDICATION FOR CHRON TX CODE (PH2)

Collection Information:

Form HXP (History Form) was completed at the entry, annual, and exit visits during both Phase 2 and Phase 3. The form is divided into two sections. The first section (questions 5-21) consists of medical history, education, household composition and income questions that were answered by the parent/primary caregiver of the patient. The second section (questions 22-31) consists of questions completed by a physician, physician's assistant, or nurse (practitioner).

Data Collection Period: 09/89 – 09/98

Form Versions: G (08/04/89)

A (09/25/90)

E (10/01/91)

K (06/22/94)

Files Used to Store Information:

SAS System File: **HXP_PUBN.SD2**

Format File: **HXP.N.FMT**

Unique Record Identifiers: **ANONID, HXID2**

Records within the dataset are sorted by **ANONID** and **HXID2**.

Number of Observations (Patients) in SAS Dataset: 3106 (467)

Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 12-20
- Listing of Variables by Position: See pp. 21-28

CSSCD Phases 2 and 3
1.1: History Form – Form HXP

Notes about Selected Variables:

- **HXCVA, HXSEIZR, HXSPLS, HXAPC, HXSEP, HXPNEU, HXMENI, HXOSTEO, HXPRI, HXSURG, HXPC, HXCMLU, HXCMPANH, HXCMPANS, HXCMPSCR:** See Section 3 for event definitions.

Inter-Relationship With Other Datasets:

- Clinical event data were also collected on

Form Abbreviation	SAS Dataset	See Section
NCVA	NCVAPUBN.SD2	3.1
CVA	CVA_PUBN.SD2	3.2
DTH	DTH_PUBN.SD2	3.5

- Transfusion data were also collected on

Form Abbreviation	SAS Dataset	See Section
NCVA	NCVAPUBN.SD2	3.1
TX*	TX_PUBN.SD2	3.4

*not collected during Phase 2

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

Deleted variable	Modified variable	Calculated using original variable, then deleted
-----------------------------	-------------------	---

COOPERATIVE STUDY OF SICKLE CELL DISEASE

HISTORY FORM

1. Person completing form (Name): _____ (Initials): **HXFC**

2. CSSCD code number of person completing form: _____ **HXCODE**

3. Date of interview (Month/Day/Year): _____ **HX_DATE** ____/____/____

4. Person interviewed (Choose **ONE** for person providing majority of answers): **HXPIN**

1. Patient 2. Parent 3. Legal Guardian 4. Other → 4.1 (specify): _____ **HXOTHPTN**

5. Is the patient currently taking, on a regular basis, any medications prescribed by a physician? **HXMEDS**

1. NO 2. YES

	5.1 TYPE OF MEDICATION: (CHECK NO OR YES FOR EACH OF A-F & H) (CHECK NO, YES, OR N/A FOR G)			5.2 IF YES, STARTED SINCE LAST STUDY VISIT?		
	1. NO	2. YES	3. N/A	1. NO	2. YES	
A. Penicillin	<input type="checkbox"/>	<input type="checkbox"/>	HXPEN	A. <input type="checkbox"/>	<input type="checkbox"/>	HXPENLV
B. Erythromycin	<input type="checkbox"/>	<input type="checkbox"/>	HXMERYTH	B. <input type="checkbox"/>	<input type="checkbox"/>	HXMERYLV
C. Folate	<input type="checkbox"/>	<input type="checkbox"/>	HXFOL	C. <input type="checkbox"/>	<input type="checkbox"/>	HXFOLLV
D. Asthma medication	<input type="checkbox"/>	<input type="checkbox"/>	HXMASM	D. <input type="checkbox"/>	<input type="checkbox"/>	HXMASMLV
↓						
SPECIFY : 5.3. _____ HXMASMT						
E. Analgesics	<input type="checkbox"/>	<input type="checkbox"/>	HXMPPN	E. <input type="checkbox"/>	<input type="checkbox"/>	HXMPPNLV
F. Iron Chelators	<input type="checkbox"/>	<input type="checkbox"/>	HXMIRC	F. <input type="checkbox"/>	<input type="checkbox"/>	HXMIRCLV
↓						
SPECIFY : 5.4. _____ HXMIRCT						
G. Oral Contraceptives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> HXCONP	G. <input type="checkbox"/>	<input type="checkbox"/>	HXCONPLV
↓						
SPECIFY : 5.5. _____ HXCONPT						
H. Other	<input type="checkbox"/>	<input type="checkbox"/>	HXMOTH	H. <input type="checkbox"/>	<input type="checkbox"/>	HXMOTHLV
↓						
SPECIFY : 5.6. _____ HXMOTHT						

6. Is the patient participating in a research protocol investigating any of the following anti-sickling therapies?

(CHECK NO OR YES TO EACH OF THE FOLLOWING)

1. NO 2. YES

6.1 Hydroxyurea

~~HXRPHYDR~~

6.2 Butyrate

~~HXRPBUTY~~

6.3 Other

→ 6.4 specify: HXOTHPRO ~~HXOTHPRE~~

~~7. Did the patient have a bone marrow transplant since the last routine study visit?~~

1. NO

2. YES

~~HXBMTB~~

8. Since the patient's last routine CSSCD study visit on _____, has the patient been seen for any clinical events or received treatment for any event?

1. NO

2. YES

HXRX

8.1 Did the patient experience?	USE CODES		8.2 Total # of unique events	8.3 # at your institution*	8.4 What was the date of the most recent event? (Month/Year)	8.5 Where was patient seen for the most recent event?				
	1. NO	2. YES				1. CSSCD Site	2. Non-CSSCD Site			
A. Stroke/TIA	<input type="checkbox"/>	HXCVA	<input type="checkbox"/>	HXCVAN	<input type="checkbox"/>	HXCVAYT	____/____	HXCVAB	<input type="checkbox"/>	HXCVAS
B. Seizures	<input type="checkbox"/>	HXSEIZR	<input type="checkbox"/>	HXSEIZN	<input type="checkbox"/>	HXSEIZYT	____/____	HXSEIZB	<input type="checkbox"/>	HXSEIZS
C. Splenic Sequestration	<input type="checkbox"/>	HXSPLS	<input type="checkbox"/>	HXSPLSN	<input type="checkbox"/>	HXSPLGYT	____/____	HXSPLGB	<input type="checkbox"/>	HXSPLS
D. Aplastic Crisis	<input type="checkbox"/>	HXAPC	<input type="checkbox"/>	HXAPCN	<input type="checkbox"/>	HXAPGYT	____/____	HXAPGB	<input type="checkbox"/>	HXAPCS
E. Sepsis	<input type="checkbox"/>	HXSEP	<input type="checkbox"/>	HXSEPN	<input type="checkbox"/>	HXSEPYT	____/____	HXSEPB	<input type="checkbox"/>	HXSEPS
F. Pneumonia/Acute Chest Syndrome	<input type="checkbox"/>	HXPNEU	<input type="checkbox"/>	HXPNEUN	<input type="checkbox"/>	HXPNEUYT	____/____	HXPNEUB	<input type="checkbox"/>	HXPNEUS
G. Meningitis	<input type="checkbox"/>	HXMENI	<input type="checkbox"/>	HXMENIN	<input type="checkbox"/>	HXMENIYT	____/____	HXMENIB	<input type="checkbox"/>	HXMENIS
H. Osteomyelitis	<input type="checkbox"/>	HXOSTEO	<input type="checkbox"/>	HXOSTEON	<input type="checkbox"/>	HXOSTEYT	____/____	HXOSTEOB	<input type="checkbox"/>	HXOSTEOS
I. Priapism	<input type="checkbox"/>	HXPRI	<input type="checkbox"/>	HXPRIIN	<input type="checkbox"/>	HXPRIYT	____/____	HXPRIIB	<input type="checkbox"/>	HXPRIIS
J. Transfusion	<input type="checkbox"/>	HXTRANS	<input type="checkbox"/>	HXTRANSN	<input type="checkbox"/>	HXTRANSY	____/____	HXTRANSB	<input type="checkbox"/>	HXTRANS
K. Surgery	<input type="checkbox"/>	HXSURG	<input type="checkbox"/>	HXSURGN	<input type="checkbox"/>	HXSURGYT	____/____	HXSURGB	<input type="checkbox"/>	HXSURGS
	8.6 IF YES, Specify: _____				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	OFFICE USE	HXSURGE
					HXSURGE					
L. Sickle Cell Pain Crisis	<input type="checkbox"/>	HXPC	<input type="checkbox"/>	HXPCN	<input type="checkbox"/>	HXPCYI	____/____	HXPCB	<input type="checkbox"/>	HXPCS
M. Other	<input type="checkbox"/>	HXOTHRX	<input type="checkbox"/>	HXOTHRXN	<input type="checkbox"/>	HXOTHRXY	____/____	HXOTHRXB	<input type="checkbox"/>	HXOTHRXS
	8.7. IF YES, Specify: _____				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	OFFICE USE	HXOTHRXC
HXOTHRXC										

* BE SURE TO COMPLETE APPROPRIATE EVENT FORM - OR - TRANSFUSION FORM
NOTE: FOR VISITS AT A NON-CSSCD CENTER, COMPLETE A MEDICAL RECORD RELEASE FORM FOR EACH UNIQUE EVENT

9. Have any of the following members of the child's family ever had:

FILL IN THE BOXES BELOW FOR 9.1 AND 9.2 USING THE CODES TO THE RIGHT

CODES
1. NO
2. YES
3. N/A

	A. Mother	B. Father	C. Sister	D. Brother	E. Grandmother	F. Grandfather
9.1 a Stroke?	<input type="checkbox"/> HXEVIISM	<input type="checkbox"/> HXEVIISF	<input type="checkbox"/> HXEVIISG	<input type="checkbox"/> HXEVIISB	<input type="checkbox"/> HXEVIISGM	<input type="checkbox"/> HXEVIISGF
9.2 Asthma?	<input type="checkbox"/> HXEVIIAM	<input type="checkbox"/> HXEVIIAF	<input type="checkbox"/> HXEVIIAS	<input type="checkbox"/> HXEVIIAB		

10. URINARY VOIDING PATTERNS

10.1. Does the patient currently have a problem with enuresis (bedwetting)?

1. NO

2. YES

HXENUR

10.1.1. How many nights per month does the patient experience enuresis (bedwetting)?

HXENURN

1. < 1 night per month

2. 1-7 nights per month

3. 8-14 nights per month

4. 15-21 nights per month

5. > 21 nights per month

10.2. Does the patient get up during the night to urinate?

1. NO

2. YES

HXGETUP

10.2.1. How many nights per month does patient get up to urinate?

HXGETUPN

1. < 1 night per month

2. 1-7 nights per month

3. 8-14 nights per month

4. 15-21 nights per month

5. > 21 nights per month

****ASK THE PARENT OF THE PATIENT TO CHOOSE ONE OF THE FOLLOWING RESPONSES FOR QUESTIONS 11-13****

RESPONSE CODES
1. Never
2. Occasionally
3. Frequently
4. Always

11. Does the patient have difficulty breathing when asleep? **HXDIFBR**
12. Does patient snore? **HXSNORE**
13. Does patient ever stop breathing while sleeping? **HXSTBR**

******FEMALES LESS THAN 8 YEARS OF AGE AND MALES SKIP TO QUESTION 16******

14. Has the patient begun her periods since her last study visit? 1. NO 2. YES **HXMPER**
- 14.1. Date begun (Month/Year):** _____ / _____ **HXMPERD**

- ~~15. Has the patient ever been pregnant?~~ 1. NO 2. YES **HXPREG**
- ~~15.1. If YES to Q.15, is the patient pregnant now?~~ 1. NO 2. YES **HXPREGN**

16. Is the patient enrolled in school? 1. NO 2. YES **HXSCH**
- HXSCHLG** 16.1 What is the last grade in school completed by the patient?
- HXREPGR** 16.2 Has the patient ever repeated a grade? 1. NO 2. YES
- HXGRREP** **16.3 Which grade? (IF MORE THAN ONE, MOST RECENT)**

17. Is the patient able to walk up 5 steps without help? By help, I mean either the help of another person, including people who live with the patient, or the help of special equipment other than the stair rail.

1. NO 2. YES HXWALK

18. Does the patient use any of the following, at least sometimes, to get around?
(CHECK NO OR YES FOR EACH OF A - E)

1. NO 2. YES

18.A. Wheelchair?		HXWHEEL
18.B. Walker?		HXWALKR
18.C. Leg brace?		HXLEGBR
18.D. Crutches?		HXCRTCH
18.E. Other?		HXOTHW

18.1 Specify: _____
_____ ~~HXOTHW~~

19. How many people live in the patient's household (unit) besides the patient?

(ENTER NUMBER) HXHSENUM

(IF ONE MENTIONED): Who is that?
(IF MORE THAN ONE): Who are they in relation to the patient?

19.1. (PROBE AT END): Anyone else?

RECORD NUMBER IN EACH BOX

19.1.A.	Mother/Stepmother	<input type="text"/>	<input type="text"/>	HXMOTHER
19.1.B.	Father/Stepfather	<input type="text"/>	<input type="text"/>	HXFATHER
19.1.C.	Sister(s)/Stepsister(s)			HX SIS
19.1.D.	Brother(s)/Stepbrother(s)			HXBRO
19.1.E.	Other female relatives			HX0THF1
19.1.F.	Other male relatives			HX0THM1
19.1.G.	Other unrelated females			HX0THF2
19.1.H.	Other unrelated males			HX0THM2
19.1.I.	TOTAL NUMBER*			HXHSETOT

*(MUST EQUAL NUMBER ENTERED ABOVE FOR QUESTION 19)

20. Counting *all* sources of income, such as Social Security, SSI, other pensions, interest, dividends, earnings, and contributions from family or other household members, which category includes the household's total *annual* income before taxes for the last calendar year?

01 Less than \$5,000	HXANINC
02 Between \$5,000 and \$9,999	
03 Between \$10,000 and \$14,999	
04 Between \$15,000 and \$19,999	
05 Between \$20,000 and \$29,999	
06 Between \$30,000 and \$49,999	
07 Between \$50,000 and \$69,999	
08 Between \$70,000 and \$99,999	

- 09 \$100,000 or more
- 77 Refused to answer
- 99 Don't know

*****FILL IN THE BOXES FOR QUESTIONS 21 AND 22 USING THE CODES BELOW.*****

CODES	
1 = No symptoms	
2 = Minor symptoms:	Minimal disruption of lifestyle (10 days or less in past 6 months)
3 = Mild symptoms:	Intermittent problems requiring confinement to home or hospital (more than 10 days in past 6 months)
4 = Moderate symptoms:	Often unable to carry out normal activities
5 = Severe symptoms:	Severely disabled, in need of care most of time

21. How would you rate the extent to which sickle cell disease has affected the patient's life in the past 6 months?

HXPFST1 Rating

***** QUESTIONS 22 - 31 ARE TO BE ANSWERED ONLY BY STUDY PERSONNEL *****

22. Rate the overall degree of disability of the patient for the past 6 months: (SEE CODES ABOVE)

HXPFST2 Rating

23. Has the patient ever experienced any of the following complications?

	1. NO	2. YES	
23.A. Leg ulcers	<input type="checkbox"/>	<input type="checkbox"/>	HXCMPLU
23.B. Aseptic necrosis (HIP)	<input type="checkbox"/>	<input type="checkbox"/>	HXCMPANH
23.C. Aseptic necrosis (SHOULDER)	<input type="checkbox"/>	<input type="checkbox"/>	HXCMPANS
23.D. Sickle cell retinopathy	<input type="checkbox"/>	<input type="checkbox"/>	HXCMPSCR

24. Is the patient currently on a chronic transfusion program?

1. NO 2. YES
↓
HXCTRN

24.1 Is this new since the patient's last study visit? 1.NO 2. YES
HXCTRNLY

24.2 Indication (CHECK NO OR YES FOR A - C)

24.2.A. Stroke 1. NO 2. YES
HXCTRNLY

24.2.B. Recurrent painful episodes 1. NO 2. YES
HXCTRNLY

24.2.C. Other 1. NO 2. YES
↓
HXCTRNO

24.2.C.1 Specify: _____
HXCTRNOT

25.1. Does the patient currently carry the diagnosis of:
(CHECK NO OR YES FOR A - Q)

1. NO 2. YES → 25.2 Year of diagnosis

A. Asthma HXASTH → 19 ~~HXASTHY~~
B. Chronic heart disease HXCHRTF → 19 ~~HXCHRTFY~~

B.1. If Yes, specify type: _____

HXCHRTFT . OFFICE USE HXCHRTFC

C. Chronic liver disease HXCLIVF → 19 ~~HXCLIVFY~~

C.1. If Yes, specify type: _____

HXCLIVFT . OFFICE USE HXCLIVFC

D. Chronic renal disease HXCREFN → 19 ~~HXCREFNY~~

D.1. If Yes, specify type: _____

HXCREFNT . OFFICE USE HXCREFNC

~~D.2. If Yes, is patient receiving dialysis? 1. NO 2. YES~~

~~E. Iron overload HXIRNOV → 19 ~~HXIRNOVY~~~~

~~F. Diabetes HXDIAB → 19 ~~HXDIABY~~~~

~~G. Rheumatic fever HXRHFV → 19 ~~HXRHFVY~~~~

~~H. Tuberculosis HXTB → 19 ~~HXTBY~~~~

~~I. Cancer HXCANG → 19 ~~HXCANGY~~~~

~~I.1. If Yes, specify type: _____~~

~~HXCANGFT . OFFICE USE HXCANGFC~~

J. Seizure HXSEIZ → 19 ~~HXSEIZY~~

K. HIV Positivity HXHIVP → 19 ~~HXHIVPY~~

L. Learning disabled HXLDIS → 19 ~~HXLDISY~~

M. Attention deficit disorder HXADD → 19 ~~HXADDY~~

25.1. Does the patient currently carry the diagnosis of:
(CHECK NO OR YES FOR A - Q)

1. NO 2. YES → 25.2 Year of diagnosis

N. Dyslexia HDYSL → 19 ~~HDYSLY~~

O. Elevated blood lead level (i.e. ever had a blood lead level ≥ 10 µg/dl?) → 19 ~~HXBLLY~~

~~P. S/P transplantation HXTRSP → 19 ~~HXTRSPY~~~~

~~P.1. If Yes, specify organ: _____~~

~~HXTRSPFT . OFFICE USE HXTRSPFC~~
HXCDIS ~~HXCDISY~~

Q. Other chronic disease

 →

19

Q.1. If Yes, specify type: _____

~~HXCBI9E~~
 OFFICE USE

~~HXCBI9E~~

26. Does the patient wear corrective lenses?

 1. NO 2. YES 3. N/A, patient blind

~~HXCORRL~~

27. Does the patient use a hearing aid?

 1. NO 2. YES 3. N/A, patient deaf

~~HXHRATD~~

28. Has the patient received an influenza (flu) virus vaccination during the past year?

 1. NO 2. YES 3. DK

~~HXFLUYR~~

***** ASK QUESTION 29 AT ENTRY AND EXIT VISITS ONLY*****

29. Has the patient ever received any of the following vaccinations?

29.2 If YES, What is the year of the most recent?

(CHECK NO , YES, OR DK (if unknown) FOR A - D)

29.1.A. H. Influenza (HIB)?

 1. NO 2. YES 9. DK

~~HXFLU
HXVPNE~~

~~HXFLUY
HXVPNE~~

29.1.B. Pneumococcus?

 1. NO 2. YES 9. DK

~~HXVHEPB
HXVMENIN~~

~~HXHEPB
HXMENTIN~~

29.1.C. Hepatitis B?

 1. NO 2. YES 9. DK

29.1.D. Meningococcus?

 1. NO 2. YES 9. DK

30. Is the patient on Special B status to be seen only at semi-annual visits and not seen for special events because of restrictions of third party payment or distance from clinic?

 1. NO 2. YES

~~HXBSTAT~~

31. Was a translator needed to complete the interview section of this form?

 1. NO 2. YES

~~HXTRSL~~

Signature of Data Coordinator: _____

Date: ____/____/____

QUESTION-BY-QUESTION SPECIFICATIONS FOR THE HISTORY FORM

Question 1. Person completing form: The person conducting the history interview should 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 person conducting the history interview is to be assigned by the Data Coordinator at each clinic.

Question 3. Date of history interview: The date the history interview was conducted should be entered in the MM/DD/YY date format (e.g., October 24, 1994, would be entered 10/24/94).

Question 4. Person interviewed: Place a check mark in the appropriate box for the person who provided the majority of answers during the history interview (check the box that best describes the person being interviewed). Please check only ONE box for a response to this question. If a check mark is placed in the “Other” box, be sure to specify who the “Other” respondent is.

Question 5. Is the patient currently taking, on a regular basis, any medications prescribed by a physician?: Ask the person being interviewed if the patient is currently taking on a regular basis, any medications prescribed by a physician and place a check mark in the appropriate box (1. NO or 2. YES). For standardization purposes, if the response to Question 5 is 2. YES, please be sure to separately probe for a response to each of the medications listed in Question 5.1 A-H. For example, *Probe: “Is the patient taking Penicillin?”, “Is the patient taking Erythromycin?”, etc.* If the answer to any of 5.1 A - H is 2. YES, be sure to ask the person being interviewed “Was the medication started since the last study visit (substitute date of last history interview)?” and check the corresponding 1. NO or 2. YES box under column 5.2.

If question 5.1.F. (Iron chelators) is answered 2. YES, be sure to ask the person interviewed “Was the medication started since the last study visit (substitute date of last history interview)?” and “What is the brand name of the iron chelator the patient is taking?” Record response in the corresponding “SPECIFY” box (Q. 5.3).

For question 5.1.G. (Oral contraceptives), you may check 3. N/A, if the patient is a male or a non menstruating female. If question 5.1 .G. is answered 2. YES, be sure to be sure to ask the person being interviewed “Was the medication started since the last study visit (substitute date of last

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM
CSSCD INFANT COHORT PATIENTS

history interview)?” and “What is the brand name of the oral contraceptive the patient is taking?”. Record the name of the oral contraceptive in the corresponding “SPECIFY~’ box (Q. 5.4) If question 5.1.1-I. (Other) is answered **2. YES**, be sure to be sure to ask the person being interviewed “Which medication(s)?” Write in the medications in the corresponding “SPECIFY” box (Q. 5.5). For each medication response, ask “Was [NAME OF MEDICATION] started since the last study visit (substitute date of last history interview)?” and record the response in the appropriate **1.NO** or **2. YES** box for 5.2.H

Question 6. Is the patient participating in a research protocol investigating any of the following anti-sickling therapies?: Ask the person being interviewed if the patient is participating in 6.1 Hydroxyurea study?, 2. Butyrate study?, or 3. some other study involving an anti-sickling drug?. Place a check mark in the **1. NO** or **2. YES** box for each of questions 6.1 - 6.3. If “Other” is answered **2. YES**, ask “What is the name of the anti-sickling therapy research protocol the patient is participating in?” Record the response on the corresponding “specify” line (Q. 6.4)

Question 7. Did the patient have a bone marrow transplant since the last routine study visit?: Place a check mark in the appropriate box, **1. NO** or **2. YES**.

Question 8. Since the patient’s last routine CSSCD study visit (substitute date of last history interview), **has the patient been seen for any clinical events or received treatment for any event?:** Place a check mark in the appropriate **1. NO** or **2. YES** box.

Question 8.1 Events A-M: If the person being interviewed answered 2. YES to question 8, then inquire about each event (A-M) separately (i.e., Did the patient experience a Stroke or TIA?, Did the patient experience any seizures?, etc.). Follow each of the event questions with its corresponding probe.

The probes for each event type are as follows:

8.I.A. By Stroke/TIA, I mean an event that a doctor called a stroke or cerebrovascular accident (CVA) which involved loss of consciousness, paralysis, visual, speech, or motor difficulties.

8.I.B. By seizures, I mean any fits or convulsions that were not associated with a stroke or meningitis (brain infection).

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

8.1.C. By Splenic Sequestration, I mean enlargement of the spleen with trapping of blood in it.

8.1.D. By Aplastic Crisis, I mean a drop in the blood count that required a transfusion.

8.1.E. By Sepsis, I mean an infection in the blood stream.

8.1.F. By Pneumonia/Acute Chest Syndrome, I mean an infection or blockage of blood flow in the lung(s).

8.1.G. By Meningitis, I mean an infection of the brain.

8.1.H. By Osteomyelitis, I mean an infection in the bones.

8.1.1. By Priapism, I mean a painful, unwanted erection of the penis lasting more than one hour.

8.1.J. By Transfusion, I mean an injection of blood into the bloodstream.

8.1.K. By Surgery, I mean an operation or a medical procedure requiring general anesthesia.

8.1.L By Sickle cell pain crisis, I mean pain in the arms, legs, back, chest, or head which lasted at least 2 hours and was not due to a cause other than sickle cell disease.

8.1.M By Other, I mean was the child seen for any other clinical events not previously mentioned?

If Surgery (8.1.K.) is answered **2. YES**, be sure to ask "What type of surgery did the patient have?" and record the response in the corresponding "Specify" box (Q. 8.6)..

If "Other" (8.1.M.) event is answered **2. YES**, be sure to ask "What other events was the patient seen for?"

If the respondent answers **2.YES** to an event in the event list, obtain the following information about the event and record the information in the appropriate corresponding boxes under columns 8.2-8.5: 8.2 Total # of unique events, 8.3 # at your institution, 8.4 most recent date of event, 8.5 most recent place seen for event.

Question 8.2 Total number of unique events: Ask "How many [NAME OF EVENT]s did (s)he have since [insert date of last history interview]?" Enter the response in box 8.2 of the corresponding event.

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM
CSSCD INFANT COHORT PATIENTS

A variety of additional prompts may be needed to obtain the information needed -to complete questions 8.3-8.5 for an event which occurred. Begin by asking the person being interviewed "When (what dates) was the patient seen for [NAME OF EVENT]?" For each date reported, ask "Where was the patient seen for the [NAME OF EVENT] on [DATE]?"

Question 8.3 Number at your institution: This box refers to the number of events that the patient was seen for at your institution from the total number of unique events that are recorded in box 8.2. Use the responses to the questions listed under Question 8.2 above to obtain the response for this question.

Question 8.4 What was the most recent date?: Use the responses to the questions listed under Question 8.2 to obtain the response for this question. Ask the person being interviewed "When (on what dates) did the patient experience the(se) [NAME OF EVENT]s?" Regardless of where the event took place, the date of the most recent event must be filled in. If the event occurred only once, record the date of that event. If the event occurred more than once, list the date of the most recent event. The date of the event should be entered in the MM/YY date format (e.g., October 24, 1994, would be entered 10/94).

Question 8.5 What hospital was patient seen at most recently?: This information will be obtained by asking the questions listed under Question 8.2 above. If the patient was seen for only one event, write in the name of the hospital the patient was seen at (even if the hospital was a CSSCD center). If the patient was seen more than once for the same event, list the name of the hospital/clinic/doctor's office where he/she was seen most recently for the event.

For each event that occurred at a non-CSSCD hospital, ask the parent/guardian to sign a Release of Medical Information Form and request records.

For events

transfusion form and submit it to the SCC. NOTE: A Cerebrovascular (CVA) Event Form should be completed for all suspected TIAs or strokes regardless of whether the patient was seen for the event at your hospital or another hospital.

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

INTERVIEW EXAMPLE

INTERVIEWER: Since Karen's last routine CSSCD study visit on April 24, 1993, has Karen been seen for any clinical events or received treatment for any event?

KAREN'S MOTHER: YES

INTERVIEWER: Did Karen experience a Stroke or TIA? By Stroke/TIA, I mean an event which a doctor called a stroke or cerebrovascular event (CVA) which involved loss of consciousness, paralysis, visual, speech, or motor difficulties.

KAREN'S MOTHER: YES, TIAs

INTERVIEWER: How many TIAs did Karen experience?

KAREN'S MOTHER: 3

INTERVIEWER: Where was Karen seen for the TIAs?

KAREN'S MOTHER: She was seen at Bay State medical Center twice and once here at Harlem Hospital.

INTERVIEWER: Can you give me the dates that Karen was seen at Bay State Medical Center because she experienced a TIA?

KAREN'S MOTHER: She was seen there for the first one in July and for another one in December 1993.

INTERVIEWER: When was she seen at Harlem because of a TIA?

KAREN'S MOTHER: On March 15, 1994

INTERVIEWER: Will you sign a Release of Medical Information Form which will allow us to obtain information about the two events that Karen was seen for at Bay State Medical Center?

KAREN'S MOTHER: Sure

Based on responses from the mother, questions 8.1.A, 8.2.A, 8.3.A, 8.4.A, 8.5.A would be filled in as follows:

8. Since the patient's last routine CSSCD study visit on _____, has the patient been seen for any clinical events or received treatment for any event?

1. NO 2. YES
↓

USE CODES				8.4 What was the date of the most recent event? (Month/Year)	8.5 Where was patient seen the most recent event? 1. CSSCD
8.1 Did the patient experience?	1. NO 2. YES	8.2 Total # of unique events	8.3 # at your institution*		

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM
CSSCD INFANT COHORT PATIENTS

2. Non-CS

A. Stroke/TIA

2

3

1

03/94

Harlem Hospit

Question 9. Have any of the following members of the child's family ever had a stroke?:

Ask the person being interviewed about each one of the individual family members listed as to having ever had a stroke. For example: "Did either of Karen's grandmothers ever have a stroke?, Did either of Karen's grandfathers ever have a stroke?" etc. Place a check mark in the appropriate **1. NO**, **2. YES**, or **3. N/A** box.

Question 10. Has enuresis (bedwetting) ever been a problem after 3 years of age?: Place a check mark in the appropriate **1. NO** or **2. YES** box. If the response to Question 10 is YES, ask "Has the bedwetting problem resolved (disappeared)?" Place a check mark in the appropriate **1.NO** or **2.YES** box. If the answer to question 10.1 is **2. YES** (enuresis has resolved), ask question 10.2 "At what age did (s)he stop wetting his/her bed?" Record the response in the appropriate boxes.

Question 11. Does the patient snore?: Place a check mark in the appropriate **1. NO** or **2.YES** box.

Question 12. Does the patient ever stop breathing while sleeping?: Place a check mark in the appropriate **1. NO** or **2.YES** box.

Question 14. Has the patient begun her periods since last study visit?: If the patient is a female less than 8 years old or is male this question does not need to be answered. You may skip directly to Question 15. For females 8 years or older, place a check mark in the appropriate box. If the person being interviewed answers **2. YES**, ask "When did the patient begin her period?" The date should be entered in the MM/YY date format (e.g., October 24, 1994, would be entered 10/94).

Question 15. Has the patient ever been pregnant?: If the patient is a female less than 8 years old or is male this question does not need to be answered. You may skip directly to Question 16. For females 8 years or older, place a check mark in the appropriate box. This question **MUST** be asked and answered, regardless of whether Question 14 is answered **1. NO** or **2. YES**. If the answer to Question 15 is **2. YES**, ask Question 15.1 "Is the patient pregnant now?" Place a check mark in the appropriate **1. NO** or **2.YES** box.

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM
CSSCD INFANT COHORT PATIENTS

Question 16. Is the patient enrolled in school?: Place a check mark in the appropriate **1. NO** or **2.YES** box. If Question 16 is answered **2. YES**, be sure to ask questions 16.1 - 16.2. If the patient is in Kindergarten, the response to Question 16 should be **2.YES** and **“N/A”** should be written in next to Question 16.1 (last grade completed).

Question 16.1 What is the last grade in school completed by the patient?: Write the grade level (i.e., if “first grade” enter “1”, etc.) in the two boxes to the right of the question. If the last grade the patient completed was kindergarten, write “0” in the boxes and make a note “kindergarten” to the side of the question.

Question 16.2 Has the patient ever repeated a grade?: Place a check mark in the appropriate box. If Question 16.2 is answered **2. YES**, Question 16.3 **MUST** be answered.

Question 16.3 Which grade?: Write the grade level (i.e., if “first grade” enter “1”, etc.) which the patient repeated in the two boxes to the right of the question. If the patient has repeated more than one grade, write in the last grade he/she repeated. If the patient repeated kindergarten, write “0” in the boxes and make a note “kindergarten” below the question.

Question 17. Is the patient able to walk up 5 steps without help?: Place a check mark in the appropriate box **1. NO** or **2. YES**.

Question 18. Does the patient use any of the following, at least sometimes, to get around?: Ask the person being interviewed about each one of the assistive devices listed (A-E) individually. For example: “Does Karen use a wheelchair, at least sometimes to get around?” Place a check mark in the appropriate **1. NO**, **2. YES**, or **3. N/A** box. If 18.E. “Other” is checked **2. YES**, be sure to ask “What else does [PATIENT’S NAME] use to get around?” and record the response on the “Specify” line (question 18.E.1).

Question 19. How many people live in the patient’s household (unit) besides the patient?: DO NOT include the patient in the answer for Question 19. Ask the person being interviewed how many people live in the patient’s household besides the patient and record that number in the boxes to the right of the question. Then ask the person being interviewed about each one of the individual household members listed as to whether they live with the patient. Record the corresponding number of the people living with the patient in the boxes to the right. Finally total up the numbers in the right column and enter this total in the boxes for 19.1.1. Remember that

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

the total number in 19.1.1. MUST equal the number entered in the boxes to the right of Question 19.

EXAMPLE

19. How many people live in the patient's household (unit) besides the patient? **(ENTER NUMBER)**

0	1
---	---

(IF ONE MENTIONED): Who is that?

(IF MORE THAN ONE): Who are they in relation to the patient?

19.1. (PROBE AT END): Anyone else?

RECORD NUMBER IN EACH BOX

19.1.A.	Mother/Stepmother		0	1
19.1.B.	Father/Stepfather		0	0
19.1.C.	Sister(s)/Stepsister(s)		0	0
19.1.D.	Brother(s)/Stepbrother(s)		0	0
19.1.E.	Other female relatives		0	0
19.1.F.	Other male relatives		0	0
19.1.G.	Other unrelated females		0	0
19.1.H.	Other unrelated males		0	0
19.1.I	TOTAL NUMBER*		0	1

*(MUST EQUAL NUMBER ENTERED ABOVE FOR QUESTION 19)

INTERVIEWER: "Does Karen's mother/stepmother live with her?"

KAREN'S MOTHER: YES

INTERVIEWER: "Does Karen's father/stepfather live with her?"

KAREN'S MOTHER: NO

ETC.

Question 20. Counting all sources of income, such as Social Security, SSI, other pensions, interest, dividends, earnings, and contributions from family or other household members, which category includes the household's total annual income before taxes for the last calendar year?: Place a check mark in the appropriate box that corresponds to the household's **TOTAL annual income**. Please check only ONE response box.

Question 21. How would you rate the extent to which sickle cell disease has affected the

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM
CSSCD INFANT COHORT PATIENTS

patient's life in the past 6 months?: Ask the person being interviewed Question 21. Using the rating scale in the box above Question 21, read each individual rating (and probe) to the person being interviewed. Record the number code that corresponds to their answer in the rating box below Question 21. The response choices for Question 21 are:

1. No symptoms
2. Minor symptoms: minimal disruption of lifestyle (10 days or less in past 6 months)
3. Mild symptoms: intermittent problems requiring confinement to home or hospital (more than 10 days in past 6 months)
4. Moderate symptoms: often unable to carry out normal activities
5. Severe symptoms: severely disabled, in need of care most of the time.

PLEASE NOTE THAT QUESTIONS 22-31 ARE TO BE ANSWERED BY STUDY PERSONNEL ONLY

Question 22. Rate the overall degree of disability of the patient for the past 6 months: Using the rating scale in the box above Question 21, record the number code that corresponds to your judgment of the patient's degree of disability in the rating box below Question 22. The response choices are listed under Question 21 above.

Question 23. Has the patient experienced any of the following complications?: Place a check mark in the appropriate box **1. NO** or **2. YES** for each of the complications listed:

- 22.A Leg ulcers
- 22.B Aseptic necrosis (HIP)
- 22.C Aseptic necrosis (SHOULDER)
- 22.D Sickle cell retinopathy.

Question 24. Is the patient currently on a chronic transfusion program?: Place a check mark in the appropriate box **1. NO** or **2. YES**. If Question 24 is answered **2. YES**, Questions 24.1 and 24.2 must be answered.

Question 24.1 Is this new since the patient's last study visit?: Place a check mark in the appropriate box **1. NO** or **2. YES**.

Question 24.2 Indication: Place a check mark in the appropriate box **1. NO** or **2. YES** for each of the indications listed: 24.2.A Stroke, 24.2.B. Recurrent painful episodes, and 24.2.C Other. If 24.2.C. is answered **2. YES**, you must specify the reason patient is receiving chronic transfusions

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM
CSSCD INFANT COHORT PATIENTS

on the "Specify" line (Q. 24.2.C.1).

Question 25.1 Does the patient carry a diagnosis of?: Place a check mark in the appropriate box **1. NO** or **2. YES** for each of the diagnoses listed (A-Q): A. Asthma, B. Chronic heart disease, C. Chronic liver disease, D. Chronic renal disease, E. Iron overload, F. Diabetes, G. Rheumatic fever, H. Tuberculosis, I. Cancer, J. Seizures, K. HIV Positivity, L. Learning disabilities, M. Attention deficit disorder, N. Dyslexia, O. Lead poisoning, P. S/P transplantation, Q. Other chronic disease. If **2. YES** is answered for any of the diagnoses, Question 25.2 (Year of diagnosis) must be filled in. The date should be entered in the YY date format (e.g., October 24, 1994, would be entered 94). For Questions **25.B, 25.C, 25.D, 25.I, 24.P,** and **24.Q.,** if any of these diagnoses is checked **2. YES,** in addition to recording the year of diagnosis you **MUST** also specify the **TYPE** of disease the patient has been diagnosed with (e.g., if chronic heart disease is **2. YES,** specify: CHF, Cardiac Hypertrophy, Cardiomyopathy, etc.). For Question 25.D, If chronic renal disease is **2. YES,** you must specify the **TYPE** of disease the patient has been diagnosed with, the year of diagnosis, **AND** answer **1. NO** or **2. YES** to Question 25.D.2 Is patient receiving dialysis?

Question 26. Does the patient wear corrective lenses?: Place a check mark in the appropriate box, **1. NO, 2. YES,** or **3. N/A,** patient blind.

Question 27. Does the patient use a hearing aid?: Place a check mark in the appropriate box, **1. NO, 2. YES,** or **3. N/A,** patient deaf.

PLEASE NOTE THAT QUESTION 29 IS TO BE ANSWERED AT ENTRY AND EXIT VISITS ONLY

Question 29. Has the patient ever received any of the following vaccinations?: Place a check mark in the appropriate box, **1. NO, 2. YES,** or **9. DK** (don't know) for the four types of vaccinations listed. If **2. YES** is answered for any of the vaccinations, you **MUST** answer Question 29.2, Year of most recent, for the corresponding vaccination. The date should be entered in the YY date format (e.g., October 24, 1994, would be entered 94).

Question 30. Is the patient on Special B status to be seen only at semi-annual visits and not seen for special events because of restrictions of third party payment or distance from clinic?: Place a check mark in the appropriate box **1.NO** or **2. YES.**

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

Question 31. Was a translator needed to complete the interview section of this form?:

Place a check mark in the appropriate box **1.NO** or **2. YES**.

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

* HXP.N.FMT contains value labels for numerical codes assigned to categorical*
* variables in the SAS dataset HXP_PUBN.SD2 *
*****;

PROC FORMAT;

VALUE HXPIN 1='PATIENT'
2='PARENT'
3='LEGAL GUARDIAN'
4='OTHER';

*Format NO_YES used for the following variables: HXMEDS HXMPEN HXMPENLV
HXMERYTH HXMERYLV HXMFOL HXMFOLLV HXMASM HXMASMLV HXMPPN HXMPPNLV
HXMIRC HXMIRCLV HXCONPLV HXMOTH HXMOTHLV HXRPHYDR HXRPBUTY
HXOTHPRO HXRX HXCVA HXSEIZR HXSPLS HXAPC HXSEP HXPNEU HXMENI
HXOSTEO HXPRI HXTRANS HXSURG HXPC HXOTHRX HXMPER
HXSCH HXREPGR HXCMLPU
HXCMPANH HXCMPANS HXCMPSCR HXCTRN HXCTRNLV HXCTRNCV HXCTRNPN
HXCTRNO HXASTH HXCHRTF HXCLIVF HXCRENF HXIRNOV HXDIAB
HXRHFV HXTB HXSEIZ HXHIVP HXLDIS HXADD HXDYSL HXEPLL
HXCDIS HXBSTAT HXTRSL HXTRNSC HXPCARE HXMIRN HXMIRNLV HXMPROPS
HXMPRLV HXRCHPRO HXPROPS HXLIVS HXSCHDIL HXTEASC HXREF HXR1
HXR2 HXR3 HXPCARE;

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

VALUE HXCONP 1='NO'
2='YES'
3='N/A'
8='N/A';

VALUE HXWALK 1='NO'
2='YES'
8='N/A-TOO YOUNG';

VALUE HXSCHDM 1='NO'
2='YES'
8='N/A-SCHOOL NOT IN SESSION';

*Format PT_SEEN used for the following variables: HXTRANSS HXPCS ;

VALUE PT_SEEN 1='CSSCD SITE'
2='NON-CSSCD SITE';

*Format CVA_ASMA used for the following variables: HXEVS HXEVA HXNOWALK;

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

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

VALUE HXENURN 1='<1 NIGHT PER MONTH'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

2='1-7 NIGHTS PER MONTH'
3='8-14 NIGHTS PER MONTH'
4='15-21 NIGHTS PER MONTH'
5='>21 NIGHT PER MONTH';

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

VALUE HXGETUPN 1='<1 NIGHT PER MONTH'
2='1-7 NIGHTS PER MONTH'
3='8-14 NIGHTS PER MONTH'
4='15-21 NIGHTS PER MONTH'
5='>21 NIGHT PER MONTH';

*Format BREATHE used for the following variables: HXDIFBR HXSNORE HXSTBR;

VALUE BREATHE 1='NEVER'
2='OCCASIONALLY'
3='FREQUENTLY'
4='ALWAYS';

VALUE HXANINC 1='LESS THAN \$5,000'
2='\$5,000 - \$9,999'
3='\$10,000 - \$14,999'
4='\$15,000 - \$19,999'
5='\$20,000 - \$29,999'
6='\$30,000 - \$49,999'
7='\$50,000 - \$69,999'
8='\$70,000 - \$99,999'
77='REFUSED TO ANSWER'
99='DO NOT KNOW';

*Format HXPFS used for the following variables: HXPFS1 HXPFS2;

VALUE HXPFS 1='NO SYMPTOMS'
2='MINOR SYMPTOMS'
3='MILD SYMPTOMS'
4='MODERATE SYMPTOMS'
5='SEVERE SYMPTOMS';

VALUE HXCORRL 1='NO'
2='YES'
3='N/A PT BLIND';

VALUE HXFLUYR 1='NO'
2='YES'
3='DOES NOT KNOW';

*Format VACCINE used for the following variables: HXFLU HXVPNE
HXVHEPB HXVMENIN;

VALUE VACCINE 1='NO'
2='YES'
9='DOES NOT KNOW';

VALUE HXREC 1='NO'
2='YES'
8='N/A NO ACTIVITIES';

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

```
VALUE HXHLTHY  1='ALL OF THE TIME'
                2='MOST OF THE TIME'
                3='SOME OF THE TIME'
                4='ALMOST NEVER'
                5='NEVER';

*Format HLTHRATE used for the following variables: HXHLTH1 HXHLTH2
HXHLTH3;

VALUE HLTHRATE  1='MUCH BETTER'
                2='SOMEWHAT BETTER'
                3='SAME'
                4='SOMEWHAT WORSE'
                5='MUCH WORSE';

VALUE HXPRINC  1='SOCIAL SECURITY'
                2='SSI OR WELFARE'
                8='JOB OF PARENT/GUARDIAN'
                9='OTH HOUSEHOLD CONTRIB'
                11='OTHER SOURCE'
                77='REFUSED TO ANSWER'
                99='DO NOT KNOW';

*Format OUTCOME used for the following variables:HXOUT1 HXOUT2 HXOUT3;

VALUE OUTCOME  1='NORMAL'
                2='ABNORMAL';

FORMAT  HXID2 HXPIN HXPIN. HXMEDS HXMPEN HXMPENLV HXMERYTH HXMERYLV
HXMFOL HXMFOLLV HXMASM HXMASMLV HXMPPN HXMPPNLV HXMIRC HXMIRCLV
HXCONPLV HXMOTH HXMOTHLV HXRPHYDR HXRPBUTY HXOTHPRO HXRX HXCVA
HXSEIZR HXSPLS HXAPC HXSEP HXPNEU HXMENI HXOSTEO HXPRI HXTRANS
HXSURG
        HXPC HXOTHRX HXMPER HXSCH HXREPGR
        HXCMPLU HXCMPANH HXCMPANS HXCMPSCR HXCTRN
        HXCTRNLV HXCTRNCV HXCTRNPV HXCTRNO HXASTH HXCHRTF HXCLIVF
HXCRENF
        HXIRNOV HXDIAB HXRHFEV HXTB HXSEIZ HXHIVP HXLDIS
        HXADD HXDYSL HXEPLL HXCDIS HXBSTAT HXTRSL HXTRNSC
        HXPCARE HXCONP HXWALK
        HXTRANS HXPCS
        HXOTHRXS PT_SEEN
        CVA_ASMA. HXENUR HXENURN
        HXGETUP HXGETUPN HXDIFBR HXSNORE HXSTBR
        BREATHE. HXPFST1 HXPFST2 HXPFS. HXANINC HXANINC. HXCORRL
        HXFLUYR HXFLU HXVPNE HXVHEPB HXVMENIN
        VACCINE HXMIRN HXMIRNLV HXMPROPS HXMPRLV
        HXRCHPRO HXPROPS HXLIVS HXSCHDIL HXTEASC HXREF HXR1-HXR3
NO_YES.
        HXSCHDM HXREC HXHLTHY HXHLTH1-HXHLTH3
        HLTHRATE. HXPRINC HXOUT1-HXOUT3 OUTCOME.;

RUN;
QUIT;
```

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 1

CSSCD INFANT COHORT PATIENTS

HXID2 ----- FOLLOW-UP IDENTIFIER

type: numeric (float)
label: HXID2
range: [1,19] units: 1
unique values: 12 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	467	1	1-PH2 ENTRY VIS
	420	3	3-PH2 ANN 1 VIS
	394	5	5-PH2 ANN 2 VIS
	378	7	7-PH2 ANN 3 VIS
	141	9	9-PH2 ANN 4 VIS
	377	11	11-PH3 ENTRY VIS
	1	12	
	323	13	13-PH3 ANN 1 VIS
	2	14	
	291	15	15-PH3 ANN 2 VIS
	295	17	17-PH3 ANN 3 VIS
	17	19	19-PH3 ANN 4 VIS

HXVERS ----- FORM VERSION

type: string (str1)
unique values: 4 coded missing: 0 / 3106

tabulation:	Freq.	Value
	411	"A"
	908	"E"
	480	"G"
	1307	"K"

HXPIN ----- 4 PERSON INTERVIEWED

type: numeric (float)
label: HXPIN
range: [1,4] units: 1
unique values: 4 coded missing: 2 / 3106

tabulation:	Freq.	Numeric	Label
	320	1	PATIENT
	2572	2	PARENT
	115	3	LEGAL GUARDIAN
	97	4	OTHER

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 1

CSSCD INFANT COHORT PATIENTS

HXOTHPIN ----- 41 OTHER PERSON INTERVIEWED SPECIFY

DELETED

type: string (str25)

unique values: 24

coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
3008	"C"	1	"GRANDFATHER"
12	"AUNT"	37	"GRANDMOTHER"
3	"BROTHER"	1	"GREAT GRANDMOTHER"
9	"CHART"	1	"MEDICAL CHART AT MRH"
1	"COUNSELOR"	1	"MOTHER'S BOYFRIEND"
2	"COUSIN"	1	"RES CARE CTR"
1	"FAMILY SERVICES"	1	"RN AT RESIDENTIAL TRTMENT"
1	"FAMLY FRIEND"	1	"SELF"
1	"FATHER"	13	"SISTER"
1	"FOSTER PARENT"	2	"STEPFATHER"
1	"FRIEND"	2	"STEPMOTHER"
1	"FROM CHART"	4	"UNCLE"

HXOTHPIN:

1. Required only if HXPIN=4

HXMEDS ----- 5 PT TAKING MEDS PRESCRIBED BY PHYSICIAN

type: numeric (float)

label: HXMEDS

range: [1,2]

units: 1

unique values: 2

coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	763	1	NO
	2343	2	YES

HXMPEN ----- 51A TAKING PENICILLIN

type: numeric (float)

label: HXMPEN

range: [1,2]

units: 1

unique values: 2

coded missing: 768 / 3106

tabulation:	Freq.	Numeric	Label
	1012	1	NO
	1326	2	YES

HXMPEN:

1. Required only if HXMEDS=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 1

CSSCD INFANT COHORT PATIENTS

HXMPENLV ----- 52A PCN STARTED SINCE LAST STUDY VISIT

type: numeric (float)
label: HXMPENLV

range: [1,2] units: 1
unique values: 2 coded missing: 1784 / 3106

tabulation:	Freq.	Numeric	Label
	1246	1	NO
	76	2	YES

HXMPENLV:

1. Required only if HXMPEN=2

HXMERYTH ----- 51B TAKING ERYTHROMYCIN

type: numeric (float)
label: HXMERYTH

range: [1,2] units: 1
unique values: 2 coded missing: 768 / 3106

tabulation:	Freq.	Numeric	Label
	2329	1	NO
	9	2	YES

HXMERYTH:

1. Required only if HXMEDS=2

HXMERYLV ----- 52B ERYTHROMYCN STARTED SINCE LAST VISIT

type: numeric (float)
label: HXMERYLV

range: [1,2] units: 1
unique values: 2 coded missing: 3093 / 3106

tabulation:	Freq.	Numeric	Label
	10	1	NO
	3	2	YES

HXMERYLV:

1. Required only if HXMERYTH=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 1

CSSCD INFANT COHORT PATIENTS

HXMFOL ----- 51C TAKING FOLATE

type: numeric (float)
label: HXMFOL

range: [1,2] units: 1
unique values: 2 coded missing: 768 / 3106

tabulation:	Freq.	Numeric	Label
	595	1	NO
	1743	2	YES

HXMFOL:

1. Required only if HXMEDS=2

HXMFOLLV ----- 52C FOLATE STARTED SINCE LAST VISIT

type: numeric (float)
label: HXMFOLLV

range: [1,2] units: 1
unique values: 2 coded missing: 1368 / 3106

tabulation:	Freq.	Numeric	Label
	1645	1	NO
	93	2	YES

HXMFOLLV:

1. Required only if HXMFOL=2

HXMASM ----- 51D TAKING ASTHMA MEDICATION

type: numeric (float)
label: HXMASM

range: [1,2] units: 1
unique values: 2 coded missing: 2227 / 3106

tabulation:	Freq.	Numeric	Label
	808	1	NO
	71	2	YES

HXMASM:

1. Required only if HXMEDS=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 1

CSSCD INFANT COHORT PATIENTS

HXMASMLV ----- 52D ASTHMA MED STARTED SINCE LAST VISIT

type: numeric (float)
label: HXMASMLV

range: [1,2] units: 1
unique values: 2 coded missing: 3039 / 3106

tabulation:	Freq.	Numeric	Label
	56	1	NO
	11	2	YES

HXMASMLV:

1. Required only if HXMASM=2

HXMASMT ----- 53 SPECIFY ASTHMA MEDICATION

MODIFIED ('ALBUTEROL', 'ALBUTEROL PUMP', 'OTHER')

type: string (str25)

unique values: 18 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
2	"."	2	"INTAL"
1	"B"	1	"INTAL, VENTOLIN"
3035	"C"	1	"METAPROTERENOL SULFATE"
45	"ALBUTEROL"	2	"PROVENTIL INHALER"
1	"ALBUTEROL PUMP"	1	"THEOPHYLLINE"
4	"BECLOMETHASONE DIPROPION"	1	"TRIAMCINOLONE"
1	"BECLOVENT"	1	"VANCERIL"
4	"CROMOLYN SODIUM"	1	"VENTOLIN"
1	"INHALER"	2	"VENTOLIN PUMP"

HXMASMT:

1. Required only if HXMASM=2

HXMPPN ----- 51E TAKING ANALGESICS

type: numeric (float)
label: HXMPPN

range: [1,2] units: 1
unique values: 2 coded missing: 771 / 3106

tabulation:	Freq.	Numeric	Label
	2048	1	NO
	287	2	YES

HXMPPN:

1. Required only if HXMEDS=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 1

CSSCD INFANT COHORT PATIENTS

HXMPPNLV ----- 52E ANALGESICS STARTED SINCE LAST VISIT

type: numeric (float)
label: HXMPPNLV

range: [1,2] units: 1
unique values: 2 coded missing: 2820 / 3106

tabulation:	Freq.	Numeric	Label
	268	1	NO
	18	2	YES

HXMPPNLV:

1. Required only if HXMPPN=2

HXMIRC ----- 51F TAKING IRON CHELATORS

type: numeric (float)
label: HXMIRC

range: [1,2] units: 1
unique values: 2 coded missing: 2190 / 3106

tabulation:	Freq.	Numeric	Label
	868	1	NO
	48	2	YES

HXMIRC:

1. Required only if HXMEDS=2 and HXVERS='K'

HXMIRCLV ----- 52F IRON CHELATOR START SINCE LAST VISIT

type: numeric (float)
label: HXMIRCLV

range: [1,2] units: 1
unique values: 2 coded missing: 3058 / 3106

tabulation:	Freq.	Numeric	Label
	34	1	NO
	14	2	YES

HXMIRCLV:

1. Required only if HXMIRC=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 1
CSSCD INFANT COHORT PATIENTS

HXMIRCT ----- 54 SPECIFY IRON CHELATOR
 type: string (str25)

unique values: 3 coded missing: 0 / 3106

tabulation: Freq. Value
 3058 "C"
 35 "DEFEROXAMINE MESYLATE"
 13 "DESFERAL"

HXMIRCT:

1. Required only if HXMIRC=2

HXCONP ----- 51G TAKING ORAL CONTRACEPTIVES
 type: numeric (float)
 label: HXCONP

range: [1,8] units: 1
unique values: 4 coded missing: 403 / 3106

tabulation: Freq. Numeric Label
 1629 1 NO
 5 2 YES
 191 3 N/A
 878 8 N/A

HXCONP:

1. Required only if HXMEDS=2 and SEX=1
2. 8 was used as code for 'N/A' on versions A,E,G, but 3 was used as code for 'N/A' on version K

HXCONPLV ----- 52G ORAL CNTRACPT START SINCE LAST VISIT
 type: numeric (float)
 label: HXCONPLV

range: [1,2] units: 1
unique values: 2 coded missing: 3100 / 3106

tabulation: Freq. Numeric Label
 3 1 NO
 3 2 YES

HXCONPLV:

1. Required only if HXCONP=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 1
CSSCD INFANT COHORT PATIENTS

DELETED

HXCONPT ----- 55 ORAL CONTRACEPTIVE SPECIFY

type: string (str25)

unique values: 6 coded missing: 0 / 3106

tabulation:	Freq.	Value
	1	"B"
	3101	"C"
	1	"ESTROGEN"
	1	"MEDROXYPROGESTERONE"
	1	"ORTHO-NOVUM"
	1	"UNKNOWN"

HXCONPT:

1. Required only if HXCONP=2

HXMOTH ----- 51H TAKING OTHER MEDICATION

type: numeric (float)

label: HXMOTH

range: [1,2] units: 1
unique values: 2 coded missing: 765 / 3106

tabulation:	Freq.	Numeric	Label
	2092	1	NO
	249	2	YES

HXMOTH:

1. Required only if HXMEDS=2

HXMOTHLV ----- 52H OTHER MED STARTED SINCE LAST VISIT

type: numeric (float)

label: HXMOTHLV

range: [1,2] units: 1
unique values: 2 coded missing: 2866 / 3106

tabulation:	Freq.	Numeric	Label
	130	1	NO
	110	2	YES

HXMOTHLV:

1. Required only if HXMOTH=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 1
 CSSCD INFANT COHORT PATIENTS

HXMOTH ----- 56 OTHER MEDICATION SPECIFY

DELETED

type: string (str25)

unique values: 76

coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
2	"B"	4	"MEDROXYPROGESTERONE"
2857	"C"	1	"MESTINON"
16	"ALBUTEROL"	3	"METHYLPHENIDATE HCL"
4	"AMITRIPTYLINE"	1	"MULTIPLE/SEE FORM"
3	"AMOXICILLIN"	27	"MULTIVITAMIN"
1	"ANTACIDS"	1	"NEUPOGEN"
1	"AUGMENTIN"	1	"NORTRIPTYLINE"
1	"BACTRIM"	1	"PERIACTIN"
1	"BECONASE/NASAL CHROM"	9	"PHENOBARBITAL"
15	"CARBAMAZEPINE"	1	"PHENYLPHRINE HCL"
4	"CEFAZOLIN"	1	"PHENYTOIN"
1	"CLARITIN"	1	"POLYVISOL"
1	"CROMOLYN SODIUM"	1	"PREDNISONE"
1	"CYCLOSPORIN"	2	"PRENATAL VITAMINS"
20	"DEFEROXAMINE MESYLATE"	1	"PROTEIN PILLS"
1	"DEPAKOTE"	1	"PROVENTIL"
1	"DEPO PROVERA"	4	"PYRIDOSTIGMINE BROMIDE"
2	"DEPOPROVERA INJECTIONS"	4	"RANDOMIZED PCN"
2	"DESMOPRESSIN ACETATE"	1	"RANITIDINE HYDROCHLORIDE"
3	"DIGOXIN"	1	"RETINOIC ACID"
1	"DIMETAPP"	1	"RITALIN"
1	"DOCUSATE SODIUM"	1	"SELDANE"
1	"ELAVIL"	1	"SEPTRA"
1	"ENALAPRIL"	3	"SUDAFED"
1	"ENALAPRIL MALEATE"	1	"SULFAMIDE OPHT."
1	"ERYTHROPOIETIN"	1	"TENEX, PAXIL"
1	"ESTROGEN"	1	"TERFENADINE"
1	"FERROUS SULFATE"	5	"THEOPHYLLINE"
1	"FLINTSTONE VIT"	1	"TRIAMCINOLONE"
1	"FLUOXETINE HYDROCHLORIDE"	1	"TYLENOL W/ CODEINE"
6	"FOLIC ACID"	1	"TYLENOL WITH CODEINE"
50	"HYDROXYUREA"	1	"VITAMIN C"
4	"IBUPROFEN"	1	"VITAMIN INJECT"
1	"IMURAN"	1	"VITAMINS"
1	"INH"	2	"VITAMINS W/IRON"
4	"ISONIAZID"	1	"VITAMINS/IRON"
1	"MAALOX"	1	"XANAX"
1	"MALARIAL PROPHY"	1	"ZOLOFT"

HXMOTH:

1. Required only if HXMOTH=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
CSSCD INFANT COHORT PATIENTS

HXRPHYDR ----- 61 PT PARTICIPATING IN HYDROXYUREA STUDY

MODIFIED SEE HXOTHPRO BELOW

type: numeric (float)
label: HXRPHYDR

range: [1,2] units: 1
unique values: 2 coded missing: 1805 / 3106

tabulation:	Freq.	Numeric	Label
	1264	1	NO
	37	2	YES

HXRPHYDR:

1. Required only if HXVERS='K'

HXRPBUTY ----- 62 PT PARTICIPATING IN BUTYRATE STUDY

type: numeric (float)
label: HXRPBUTY

range: [1,1] units: 1
unique values: 1 coded missing: 1805 / 3106

tabulation:	Freq.	Numeric	Label
	1301	1	NO

HXRPBUTY:

1. Required only if HXVERS='K'

HXOTHPRO ----- 63 PT PARTICIPATING IN OTHER STUDY

MODIFIED: HXOTHPRO=2 IF HXRPHYDR=2

type: numeric (float)
label: HXOTHPRO

range: [1,2] units: 1
unique values: 2 coded missing: 1392 / 3106

tabulation:	Freq.	Numeric	Label
	1642	1	NO
	72	2	YES

HXOTHPRO:

1. Required only if HXVERS='K' or HXRCHPRO=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
 CSSCD INFANT COHORT PATIENTS

HXOTHPR1 ----- 64 OTHER STUDY SPECIFY

DELETED

type: string (str25)

unique values: 19

coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
1	"."	1	"HIB LOCAL STUDY"
3034	"C"	10	"LOCAL"
1	"CENTER STUDYS NO RX"	19	"NASOPHARYNGEAL STUDY"
1	"CNS STUDY"	1	"NOT RX PROTOCOLS"
1	"COPING"	3	"PRE-OP TRANSFUSION"
1	"FLOGOR S. PHASE 3"	1	"SPRANS II"
1	"GROWTH HORMONE STUDY"	1	"STOP"
14	"HIB CONJUGATE STUDY"	5	"STOP STUDY"
1	"HIB CONJUGATE/PRAXIS"	8	"TRANSFUSION STUDY"
		2	"WILM'S TUMOR STUDY"

HXOTHPR1:

1. Required only if HXOTHPR0=2

HXBMTR ----- 7 BONE MARROW TRANSPLNT SINCE LAST VISIT

DELETED

type: numeric (float)

label: HXBMTR

range: [1,2]

units: 1

unique values: 2

coded missing: 1823 / 3106

tabulation:	Freq.	Numeric	Label
	1282	1	NO
	1	2	YES

HXBMTR:

1. Required only if HXVERS='K'

HXR1 ----- 8 SINCE LAST VISIT PT SEEN FOR ANY EVENT

type: numeric (float)

label: HXR1

range: [1,2]

units: 1

unique values: 2

coded missing: 3 / 3106

tabulation:	Freq.	Numeric	Label
	2302	1	NO
	801	2	YES

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

HXCVA ----- 81A PT EXPERIENCE STROKE/TIA

type: numeric (float)
label: HXCVA
range: [1,2] units: 1
unique values: 2 coded missing: 2309 / 3106

tabulation:	Freq.	Numeric	Label
	782	1	NO
	15	2	YES

HXCVA:

1. Required only if HXRX=2

HXCVAN ----- 82A TOTAL # UNIQUE EVENTS STROKE/TIA

type: numeric (float)
range: [1,8] units: 1
unique values: 3 coded missing: 3091 / 3106

tabulation:	Freq.	Value
	13	1
	1	2
	1	8

HXCVAN:

1. Required only if HXCVA=2

HXCVAYI ----- 83A # STROKE/TIA AT YOUR INSTITUTION

DELETED

type: numeric (float)
range: [0,2] units: 1
unique values: 3 coded missing: 3097 / 3106

tabulation:	Freq.	Value
	1	0
	6	1
	2	2

HXCVAYI:

1. Required only if HXCVA=2 and HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
CSSCD INFANT COHORT PATIENTS

HXCVAS ----- 85A WHERE SEEN FOR MOST RECENT STROKE

DELETED

type: numeric (float)
label: HXCVAS
range: [1,2] units: 1
unique values: 2 coded missing: 3097 / 3106

tabulation:	Freq.	Numeric	Label
	8	1	CSSCD SITE
	1	2	NON-CSSCD SITE

HXCVAS:

1. Required only if HXCVA=2 and HXVERS='K'

HXSEIZR ----- 81B PT EXPERIENCE SEIZURES

type: numeric (float)
label: HXSEIZR
range: [1,2] units: 1
unique values: 2 coded missing: 2471 / 3106

tabulation:	Freq.	Numeric	Label
	634	1	NO
	1	2	YES

HXSEIZR:

1. Required only if HXR=2

HXSEIZN ----- 82B TOTAL # UNIQUE EVENTS SEIZURES

type: numeric (float)
range: [1,1] units: 1
unique values: 1 coded missing: 3105 / 3106

tabulation:	Freq.	Value
	1	1

HXSEIZN:

1. Required only if HXSEIZR=2

HXSEIZYI ----- 83B # SEIZURES AT YOUR INSTITUTION

DELETED

type: numeric (float)
range: [1,1] units: 1
unique values: 1 coded missing: 3105 / 3106

tabulation:	Freq.	Value
	1	1

HXSEIZYI:

1. Required only if HXSEIZR=2 and HXVERS='K'

HXSEIZS ----- 85B WHERE SEEN FOR MOST RECENT SEIZURE

DELETED

type: numeric (float)
label: HXSEIZS
range: [1,1] units: 1
unique values: 1 coded missing: 3105 / 3106

tabulation:	Freq.	Numeric	Label
	1	1	CSSCD SITE

HXSEIZS: 1. Required only if HXSEIZR=2 and HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
CSSCD INFANT COHORT PATIENTS

HXSPLS ----- 81C PT EXPERIENCE SPLENIC SEQUESTRATION

type: numeric (float)
label: HXSPLS
range: [1,2] units: 1
unique values: 2 coded missing: 2309 / 3106
tabulation: Freq. Numeric Label
783 1 NO
14 2 YES

HXSPLS:
1. Required only if HXRX=2

HXSPLSN ----- 82C TOTAL # UNIQUE EVENTS SPLEN SEQUEST

type: numeric (float)
range: [1,2] units: 1
unique values: 2 coded missing: 3093 / 3106
tabulation: Freq. Value
9 1
4 2

HXSPLSN:
1. Required only if HXSPLS=2

HXSPLSYI ----- 83C # SPLEN SEQUEST AT YOUR INSTITUTION

type: numeric (float)
range: [1,1] units: 1
unique values: 1 coded missing: 3100 / 3106
tabulation: Freq. Value
6 1

DELETED

HXSPLSYI:
1. Required only if HXSPLS=2 and HXVERS='K'

HXSPLSS ----- 85C WHERE SEEN FOR MOST RECENT S SEQUEST

type: numeric (float)
label: HXSPLSS
range: [1,1] units: 1
unique values: 1 coded missing: 3100 / 3106
tabulation: Freq. Numeric Label
6 1 CSSCD SITE

DELETED

HXSPLSS:
1. Required only if HXSPLS=2 and HXVERS='K'

HXAPC ----- 81D PT EXPERIENCE APLASTIC CRISIS

type: numeric (float)
label: HXAPC
range: [1,2] units: 1
unique values: 2 coded missing: 2471 / 3106

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

tabulation: Freq. Numeric Label
611 1 NO
24 2 YES

HXAPC:

- 1. Required only if HXRX=2 and HXVERS='K'

HXAPCN ----- 82D TOTAL # UNIQUE EVENTS APLAST CRISIS

type: numeric (float)

range: [1,1] units: 1
unique values: 1 coded missing: 3083 / 3106

tabulation: Freq. Value
23 1

HXAPCN:

- 1. Required only if HXAPC=2

HXAPCYI ----- 83D # APLAST CRISIS AT YOUR INSTITUTION

type: numeric (float)

range: [0,2] units: 1
unique values: 3 coded missing: 3084 / 3106

tabulation: Freq. Value
2 0
19 1
1 2

DELETED

HXAPCYI:

- 1. Required only if HXAPC=2

HXAPCS ----- 85D WHERE SEEN FOR MOST RECENT APLASTIC

type: numeric (float)
label: HXAPCS

range: [1,2] units: 1
unique values: 2 coded missing: 3082 / 3106

tabulation: Freq. Numeric Label
19 1 CSSCD SITE
5 2 NON-CSSCD SITE

DELETED

HXAPCS:

- 1. Required only if HXAPC=2

HXSEP ----- 81E PT EXPERIENCE SEPSIS

type: numeric (float)
label: HXSEP

range: [1,2] units: 1
unique values: 2 coded missing: 2309 / 3106

tabulation: Freq. Numeric Label
782 1 NO
15 2 YES

HXSEP:

- 1. Required only if HXRX=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
CSSCD INFANT COHORT PATIENTS

HXSEPN ----- 82E TOTAL # UNIQUE EVENTS SEPSIS

type: numeric (float)
range: [1,2] units: 1
unique values: 2 coded missing: 3092 / 3106

tabulation: Freq. Value
12 1
2 2

HXSEPN:

1. Required only if HXSEP=2

HXSEPYI ----- 83E # SEPSIS AT YOUR INSTITUTION

DELETED

type: numeric (float)
range: [1,2] units: 1
unique values: 2 coded missing: 3096 / 3106

tabulation: Freq. Value
9 1
1 2

HXSEPYI:

1. Required only if HXSEP=2 and HXVERS='K'

HXSEPS ----- 85E WHERE SEEN FOR MOST RECENT SEPSIS

DELETED

type: numeric (float)
label: HXSEPS
range: [1,2] units: 1
unique values: 2 coded missing: 3095 / 3106

tabulation: Freq. Numeric Label
10 1 CSSCD SITE
1 2 NON-CSSCD SITE

HXSEPS:

1. Required only if HXSEP=2 and HXVERS='K'

HXPNEU ----- 81F PT EXPERIENCE PNEUMONIA/ACUTE CHEST

type: numeric (float)
label: HXPNEU
range: [1,2] units: 1
unique values: 2 coded missing: 2308 / 3106

tabulation: Freq. Numeric Label
622 1 NO
176 2 YES

HXPNEU:

1. Required only if HXRX=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
CSSCD INFANT COHORT PATIENTS

HXPNEUN ----- 82F TOTAL # UNIQUE EVENTS PNEUMONIA/ACS

type: numeric (float)
range: [1,5] units: 1
unique values: 5 coded missing: 2933 / 3106

tabulation:	Freq.	Value
	133	1
	26	2
	11	3
	2	4
	1	5

HXPNEUN:
1. Required only if HXPNEU=2

HXPNEUYI ----- 83F # PNEUMONIA/ACS AT YOUR INSTITUTION

DELETED

type: numeric (float)
range: [0,5] units: 1
unique values: 6 coded missing: 2976 / 3106

tabulation:	Freq.	Value
	15	0
	88	1
	19	2
	5	3
	2	4
	1	5

HXPNEUYI:
1. Required only if HXPNEU=2 and HXVERS='K'

HXPNEUS ----- 85F WHERE SEEN FOR MOST RECENT PNEUMONIA

DELETED

type: numeric (float)
label: HXPNEUS
range: [1,2] units: 1
unique values: 2 coded missing: 2978 / 3106

tabulation:	Freq.	Numeric	Label
	113	1	CSSCD SITE
	15	2	NON-CSSCD SITE

HXPNEUS:
1. Required only if HXPNEU=2 and HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

HXMENI ----- 81G PT EXPERIENCE MENINGITIS

type: numeric (float)
label: HXMENI

range: [1,2] units: 1
unique values: 2 coded missing: 2309 / 3106

tabulation:	Freq.	Numeric	Label
	796	1	NO
	1	2	YES

HXMENI:

1. Required only if HXRX=2

HXMENIN ----- 82G TOTAL # UNIQUE EVENTS MENINGITIS

type: numeric (float)

range: [1,1] units: 1
unique values: 1 coded missing: 3105 / 3106

tabulation:	Freq.	Value
	1	1

HXMENIN:

1. Required only if HXMENI=2

HXMENIYI ----- 83G # MENINGITIS AT YOUR INSTITUTION

type: numeric (float)

range: [.,.] units: .
unique values: 0 coded missing: 3106 / 3106

tabulation: Freq. Value
Value missing for all patients

HXMENIYI:

1. Required only if HXMENI=2 and HXVERS='K'

DELETED

HXMENIS ----- 85G WHERE SEEN FOR MOST RECENT MENINGITS

type: numeric (float)
label: HXMENIS

range: [2,2] units: 1
unique values: 1 coded missing: 3105 / 3106

tabulation:	Freq.	Numeric	Label
	1	2	NON-CSSCD SITE

HXMENIS:

1. Required only if HXMENI=2 and HXVERS='K'

DELETED

HXOSTEO ----- 81H PT EXPERIENCE OSTEOMYELITIS

type: numeric (float)
label: HXOSTEO

range: [1,1] units: 1
unique values: 1 coded missing: 2402 / 3106

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

tabulation: Freq. Numeric Label
704 1 NO

HXOSTEO:

1. Required only if HXRX=2

HXOSTEON ----- 82H TOTAL # UNIQUE EVENTS OSTEOMYELITIS

type: numeric (float)

range: [.,.] units: .
unique values: 0 coded missing: 3106 / 3106

tabulation: Freq. Value
Value missing for all patients

HXOSTEON:

1. Required only if HXOSTEO=2

HXOSTEYI ----- 83H # OSTEOMYELITIS AT YOUR INSTITUTION

DELETED

type: numeric (float)

range: [.,.] units: .
unique values: 0 coded missing: 3106 / 3106

tabulation: Freq. Value
Value missing for all patients

HXOSTEYI:

1. Required only if HXOSTEO=2 and HXVERS='K'

HXOSTEOS ----- 85H WHERE SEEN FOR MOST RECENT OSTEOMYEL

DELETED

type: numeric (float)
label: HXOSTEOS

range: [.,.] units: .
unique values: 0 coded missing: 3106 / 3106

tabulation: Freq. Numeric Label
Value missing for all patients

HXOSTEOS:

1. Required only if HXOSTEO=2 and HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

HXPRI ----- 81I PT EXPERIENCE PRIAPISM

type: numeric (float)
label: HXPRI
range: [1,2] units: 1
unique values: 2 coded missing: 2358 / 3106

tabulation:	Freq.	Numeric	Label
	737	1	NO
	11	2	YES

HXPRI:

1. Required only if HXRX=2 and SEX=2

HXPRI ----- 82I TOTAL # UNIQUE EVENTS PRIAPISM

type: numeric (float)
range: [1,3] units: 1
unique values: 3 coded missing: 3095 / 3106

tabulation:	Freq.	Value
	8	1
	2	2
	1	3

HXPRI:

1. Required only if HXPRI=2

HXPRIYI ----- 83I # PRIAPISM AT YOUR INSTITUTION

DELETED

type: numeric (float)
range: [1,3] units: 1
unique values: 3 coded missing: 3098 / 3106

tabulation:	Freq.	Value
	6	1
	1	2
	1	3

HXPRIYI:

1. Required only if HXPRI=2 and HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
 CSSCD INFANT COHORT PATIENTS

HXPRIIS ----- 85I WHERE SEEN FOR MOST RECENT PRIAPISM

DELETED

type: numeric (float)
 label: HXPRIIS

range: [1,1] units: 1
 unique values: 1 coded missing: 3098 / 3106

tabulation:	Freq.	Numeric	Label
	8	1	CSSCD SITE

HXPRIIS:
 1. Required only if HXPRI=2 and HXVERS='K'

HXTRANS ----- 81J PT HAVE TRANSFUSION

type: numeric (float)
 label: HXTRANS

range: [1,2] units: 1
 unique values: 2 coded missing: 2304 / 3106

tabulation:	Freq.	Numeric	Label
	580	1	NO
	222	2	YES

HXTRANS:
 1. Required only if HXRX=2

HXTRANSN ----- 82J TOTAL # UNIQUE EVENTS TRANSFUSION

GROUPED
SEE PAGES 1-8

type: numeric (float)

range: [1,37] units: 1
 unique values: 21 coded missing: 2893 / 3106

tabulation:			
Freq.	Value	Freq.	Value
85	1	4	11
31	2	11	12
15	3	2	13
4	4	7	14
4	5	1	16
8	6	3	17
5	7	1	18
5	8	2	19
9	9	2	20
12	10	1	30
		1	37

HXTRANSN:
 1. Required only if HXTRANS=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

HXSURGC ----- SURGERY ICD-9 CODE

DELETED

type: numeric (float)

range: [2.02,999.99]

units: .01

unique values: 23

coded missing: 3058 / 3106

tabulation:

Freq.	Value
1	2.02
1	14.29
1	20.01
1	28.2
5	28.3
1	38.85
4	38.93
1	39.5
1	41
2	41.5
16	51.22

Freq.	Value
1	51.23
1	53
2	55.23
1	64
2	64.98
1	77.15
1	79.27
1	80.21
1	86.04
1	86.3
1	789
1	999.99

HXSURGC:

1. Required only if HXSURG=2
2. See ICD-9 codebook for procedure codes

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

HXSURGN ----- 82K TOTAL # UNIQUE EVENTS SURGERY
type: numeric (float)

range: [1,3] units: 1
unique values: 3 coded missing: 3056 / 3106

tabulation:	Freq.	Value
	46	1
	3	2
	1	3

HXSURGN:

1. Required only if HXSURG=2

HXSURGYI ----- 83K # SURGERIES AT YOUR INSTITUTION

DELETED

type: numeric (float)

range: [0,3] units: 1
unique values: 4 coded missing: 3064 / 3106

tabulation:	Freq.	Value
	4	0
	35	1
	2	2
	1	3

HXSURGYI:

1. Required only if HXSURG=2 and HXVERS='K'

HXSURGS ----- 85K WHERE SEEN FOR MOST RECENT SURGERY

DELETED

type: numeric (float)
label: HXSURGS

range: [1,2] units: 1
unique values: 2 coded missing: 3063 / 3106

tabulation:	Freq.	Numeric	Label
	38	1	CSSCD SITE
	5	2	NON-CSSCD SITE

HXSURGS:

1. Required only if HXSURG=2 and HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
 CSSCD INFANT COHORT PATIENTS

HXPC ----- 81L PT EXPERIENCE SICKLE PAIN CRISIS

type: numeric (float)
 label: HXPC
 range: [1,2] units: 1
 unique values: 2 coded missing: 2475 / 3106

tabulation:	Freq.	Numeric	Label
	188	1	NO
	443	2	YES

HXPC:

1. Required only if HXR=2 and HXVERS='K'

HXPCN ----- 82L TOTAL # UNIQUE EVENTS PAIN CRISIS

GROUPED
SEE PAGES 1-8

type: numeric (float)
 range: [1,39] units: 1
 unique values: 17 coded missing: 2671 / 3106

tabulation:

Freq.	Value	Freq.	Value
197	1	6	9
96	2	6	10
48	3	4	11
28	4	3	12
20	5	1	13
8	6	1	14
9	7	3	15
3	8	1	30
		1	39

HXPCN:

1. Required only if HXPC=2

HXPCYI ----- 83L # PAIN CRISES AT YOUR INSTITUTION

GROUPED
SEE PAGES 1-8

type: numeric (float)
 range: [0,15] units: 1
 unique values: 16 coded missing: 2672 / 3106

tabulation:

Freq.	Value	Freq.	Value
41	0	3	8
194	1	5	9
84	2	3	10
39	3	3	11
28	4	2	12
16	5	1	13
5	6	1	14
7	7	2	15

HXPCYI:

1. Required only if HXPC=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

HXPCS ----- 85L WHERE SEEN FOR MOST RECENT CRISIS

type: numeric (float)
 label: HXPCS

range: [1,2] units: 1
 unique values: 2 coded missing: 2675 / 3106

tabulation:	Freq.	Numeric	Label
	385	1	CSSCD SITE
	46	2	NON-CSSCD SITE

HXPCS:

1. Required only if HXPC=2

HXOTHRX ----- 81M PT EXPERIENCE OTHER

type: numeric (float)
 label: HXOTHRX

range: [1,2] units: 1
 unique values: 2 coded missing: 2311 / 3106

tabulation:	Freq.	Numeric	Label
	456	1	NO
	339	2	YES

HXOTHRX:

1. Required only if HXR=2

HXOTHRT ----- 87 OTHER EVENT SPECIFY

type: string (str25)

unique values: 171 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
3	."	1	"ARM FRACTURE"
1	"A"	2	"ASEPTIC NECROSIS"
1	"B"	13	"ASTHMA"
2767	"C"	1	"AUTO ACCIDENT INJURY"
2	"ABDOMINAL PAIN"	1	"AVASCULAR NECROSIS HIP"
1	"ACHILLES TENDONITIS"	1	"AVASCULAR NECROSIS L HIP"
1	"ACROMIUM FRACTURE"	1	"BACK PAIN"
1	"ACUTE ANEMIA"	1	"BACTEREMIA"
2	"ACUTE FEBRILE ILLNESS"	1	"BILE DUCT STONE"
1	"ACUTE GASTROENTERITIS"	1	"BLACK OUTS"
1	"ACUTE PHARYNGITIS"	1	"BLOOD TX REACTION"
1	"ACUTE RENAL FAILURE"	1	"BOM"
1	"ALLERGIC RXN - EYES"	1	"BONE INFARCTION"
2	"ANEMIA"	1	"BRIEF/INTRMITNT PALPITATN"
1	"ANEMIC EPISODE"	3	"BRONCHITIS"
1	"ANKLE SPRAIN"	1	"BURNED FINGER"
4	"APLASTIC CRISIS"	1	"CELLULITIS L ELBOW"

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
 CSSCD INFANT COHORT PATIENTS

HX0THRT(cont'd) ----- 87 OTHER EVENT SPECIFY
 type: string (str25)

unique values: 171

coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
1	"CELLULITIS L FOOT"	1	"HEADACHES"
1	"CELLULITIS OF R ARM"	5	"HEMATURIA"
1	"CELLULITIS RIGHT THIGH"	1	"HEMOLYTIC CRISIS"
1	"CHEST PAIN"	1	"HERPES SIMPLEX R LOW LIP1"
1	"CHF"	1	"HIP PAIN"
1	"CHICKEN POX"	1	"HIT BY CAR"
1	"CHILDBIRTH"	1	"HYPHEMA R EYE"
1	"CHOLECYSTITIS"	1	"HYPOVOLEMIA W/ VOMITING"
1	"CHOLEDOCHOLITHIASIS"	1	"INFECTED R EXTERNAL EAR"
1	"CHRONIC SINUSITIS"	3	"INFECTIOUS ENTERITIS"
1	"CONJUNCTIVITIS"	1	"INTRAMEDULARY SPINAL CYST"
1	"CONSTIPATION"	1	"L ANKLE SPRAIN"
1	"COUGH"	1	"L ARM INJURY"
1	"CRISIS ? BONE INFARC"	1	"L GROIN SWELLING"
1	"CUT FINGER/STITCHES"	1	"LACERATION TO VULVA-FELL"
1	"CUT LEG"	1	"LACERATION/FINGER"
1	"DEHYDRATION"	1	"LEG PAIN"
1	"DELIVERY"	1	"LOM"
1	"DESFERAL CHALLENGE"	1	"LT FOREARM INJURY"
1	"DOG BITE R LEG"	1	"LUPUS"
1	"DROP IN HB"	1	"MISCARRIAGE"
1	"DYSURIA"	1	"MORPHINE HALLUCINATIONS"
2	"EAR INFECTION"	1	"MYASTHENIA GRAVIS"
1	"EFFUSION L ELBOW"	1	"NEPHRITIS"
1	"EPILEPSY"	1	"OBSTRUCTED BILE DUCT"
1	"FACE SWELLING"	1	"ORTHOPEDIC CLINIC"
1	"FEBRILE"	6	"OTITIS MEDIA"
3	"FEBRILE ILLNESS"	20	"PAIN"
14	"FEVER"	17	"PAIN CRISIS"
1	"FEVER R/O SEPSIS"	1	"PAIN EVENT"
1	"FEVER UNKNOWN SOURCE"	1	"PAIN IN CHEST"
22	"FEVER W/O SOURCE"	2	"PAINFUL EPISODE"
1	"FEVER W/OUT SOURCE"	1	"PAINFUL EPISODES"
1	"FEVER WITHOUT SOURCE"	1	"PERIORBITAL CELLULITIS"
1	"FEVER,DESATURATION,ACUTE"	14	"PHARYNGITIS"
1	"FRACTURE R WRIST"	1	"PORT-A-CATH INFECTION X2"
1	"FRACTURED FEMUR"	1	"POS TB TEST"
1	"FRACTURED NAVICULAR"	1	"POSS PAPILLARY NECROSIS"
1	"FRACTURED PHALANX"	1	"POST-ABORTION/MISCARRIAGE"
1	"FRACTURED R WRIST"	1	"PREGNANCY"
2	"FUO"	1	"PREGNANCY DELIVERY"
1	"FX WRIST"	1	"PREGNANCY/DELIVERY"
1	"GALLSTONES"	1	"PRURITIC DISORDER"
1	"GASTRITIS"	1	"PSYCH ADMIT-SUICIDE"
1	"HAND SWELLING WT ULCER"	1	"PSYCHO COUNSELING"
1	"HEAD CONCUSSION"	1	"PSYCHOTIC EPISODE"
1	"HEADACHE"	1	"PULMONARY HTN"

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
 CSSCD INFANT COHORT PATIENTS

HXOTHRT(cont'd) ----- 87 OTHER EVENT SPECIFY
 type: string (str25)

unique values: 171 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
1	"PYELONEPHRITIS"	1	"SPONTANEOUS ABORTION"
1	"R 2ND TOE FX"	1	"SPRAINED ANKLE"
1	"R ANKLE SPRAIN"	1	"SPRAINED FINGER"
1	"R EYE CELLULITIS"	3	"STREP PHARYNGITIS"
1	"R EYE CONTUSION"	3	"STREP THROAT"
1	"R/O NEW CVA"	1	"SWELLING OF HANDS"
2	"REACTIVE AIRWAY DISEASE"	1	"SWOLLEN EYES"
1	"REACTIVE AIRWAY DZ"	1	"SWOLLEN L HAND"
1	"RENAL HYPERTENSION"	1	"SX FOR PRIAPISM"
1	"RT OTITIS MEDIA"	4	"SYNCOPE"
1	"RUA - CHOLELITHIASIS"	4	"TONSILAR PHARYNGITIS"
1	"RUQ"	6	"TONSILITIS"
1	"RUQ/GALLSTONES"	13	"URI"
1	"SALMONELLA GASTROENT"	1	"URINARY RETENTION"
1	"SCALP LESIONS"	9	"UTI"
1	"SEIZURE NON-FEBRILE"	9	"VASOOCCLUSIVE CRISIS"
1	"SILENT INFARCT"	2	"VIRAL SYNDROME"
1	"SINUSITIS"	1	"VOMITING"
4	"SORE THROAT"	1	"VOMITING/WHEEZING"
1	"SORE THROAT/BSTREP A"	1	"VTI"
1	"SPLENOMEGALY"	1	"WHEEZING"
		1	"WOUND TO LIP"

HXOTHRT:

1. Required only if HXOTHRX=2

HXOTHRXC ----- OTHER EVENT ICD-9 CODE

type: numeric (float)

range: [9.1,999.99] units: .01
 unique values: 103 coded missing: 2773 / 3106

GROUPED
SEE PAGES 1-8

tabulation:

Freq.	Value	Freq.	Value	Freq.	Value	Freq.	Value
3	9.1	1	298.9	1	416	1	535.5
7	34	1	300.9	1	428	1	558.9
1	52.9	1	345.9	1	461.9	1	564
1	54.9	1	349.2	19	462	4	574.2
1	64.98	1	358	6	463	1	574.31
2	79.99	1	364.41	4	465.8	2	574.5
1	99.29	1	372.3	13	465.9	1	575.1
2	276.5	3	376.01	1	466	1	583.9
54	282.62	1	376.33	1	473	1	584.7
3	284.9	1	380.89	14	493.9	1	584.9
4	285.9	11	382.9	1	493.91	1	590.1
1	292.12	1	403.9	3	519.8	10	599

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 2
 CSSCD INFANT COHORT PATIENTS

HX0THRXC(cont'd) ----- OTHER EVENT ICD-9 CODE **GROUPED**
 type: numeric (float) **SEE PAGES 1-8**

range: [9.1,999.99] units: .01
 unique values: 103 coded missing: 2773 / 3106

tabulation:

Freq.	Value	Freq.	Value	Freq.	Value	Freq.	Value
5	599.7	1	726.71	2	787	1	826
1	624.9	1	729.5	1	788.1	1	842.1
1	634.5	2	729.81	1	788.2	4	845
2	634.9	4	733.42	2	789	1	850.9
5	650	1	739	1	789.2	1	873.43
2	682.3	5	780.2	1	789.3	2	883
1	682.6	46	780.6	1	790.7	1	890
1	682.7	2	784	1	795.5	1	891
1	698.9	1	785.1	1	811.01	1	921.9
1	710	1	786.09	3	814	1	944.01
1	719.02	2	786.2	1	814.01	1	955.9
1	724.3	1	786.5	1	816	1	959.9
1	724.5	1	786.6	1	818	1	995.3
						1	999.6
						1	999.8
						12	999.99

HX0THRXC:
 1. Required only if HX0THR=2
 2. See ICD-9 codebook for disease codes

HX0THRXN ----- 82M TOTAL # UNIQUE EVENTS OTHER **GROUPED**
 type: numeric (float) **SEE PAGES 1-8**

range: [1,12] units: 1
 unique values: 9 coded missing: 2782 / 3106

tabulation:

Freq.	Value
227	1
58	2
21	3
8	4
5	5
2	6
1	7
1	10
1	12

HX0THRXN:
 1. Required only if HX0THR=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 2

CSSCD INFANT COHORT PATIENTS

HXOTHRXY ----- 83M # OTHER EVENTS AT YOUR INSTITUTION
type: numeric (float)

range: [0,12] units: 1
unique values: 9 coded missing: 2879 / 3106

tabulation: Freq. Value
14 0
134 1
47 2
19 3
6 4
4 5
1 6
1 7
1 12

HXOTHRXY:

1. Required only if HXOTHRX=2 and HXVERS='K'

HXOTHRXS ----- 85M WHERE SEEN FOR MOST RECENT OTHER EV
type: numeric (float)
label: HXOTHRXS

DELETED

range: [1,2] units: 1
unique values: 2 coded missing: 2874 / 3106

tabulation: Freq. Numeric Label
210 1 CSSCD SITE
22 2 NON-CSSCD SITE

HXOTHRXS:

1. Required only if HXOTHRX=2 and HXVERS='K'

CALCULATED VARIABLE - HXEVHS: FAMILY HISTORY OF STROKE
SEE PAGES 1-8

HXEVHSM ----- 91A HAS MOTHER EVER HAD A STROKE

type: numeric (float)
label: HXEVHSM

range: [1,3] units: 1
unique values: 3 coded missing: 1821 / 3106

tabulation:	Freq.	Numeric	Label
	1274	1	NO
	7	2	YES
	4	3	N/A

HXEVHSM:
1. Required only if HXVERS='K'

CALCULATED VARIABLE - HXEVHS: FAMILY HISTORY OF STROKE
SEE PAGES 1-8

HXEVHSF ----- 91B HAS FATHER EVER HAD A STROKE

type: numeric (float)
label: HXEVHSF

range: [1,3] units: 1
unique values: 3 coded missing: 1822 / 3106

tabulation:	Freq.	Numeric	Label
	1253	1	NO
	22	2	YES
	9	3	N/A

HXEVHSF:
1. Required only if HXVERS='K'

CALCULATED VARIABLE - HXEVHS: FAMILY HISTORY OF STROKE
SEE PAGES 1-8

HXEVHSS ----- 91C HAS SISTER EVER HAD A STROKE

type: numeric (float)
label: HXEVHSS

range: [1,3] units: 1
unique values: 3 coded missing: 1821 / 3106

tabulation:	Freq.	Numeric	Label
	1107	1	NO
	6	2	YES
	172	3	N/A

HXEVHSS:
1. Required only if HXVERS='K'

CALCULATED VARIABLE - HXEVHS: FAMILY HISTORY OF STROKE
SEE PAGES 1-8

HXEVHSB ----- 91D HAS BROTHER EVER HAD A STROKE

type: numeric (float)
label: HXEVHSB

range: [1,3] units: 1
unique values: 3 coded missing: 1823 / 3106

tabulation:	Freq.	Numeric	Label
	1101	1	NO
	13	2	YES
	169	3	N/A

HXEVHSB:
1. Required only if HXVERS='K'

HXEVHSGM ----- 91E HAS GRANDMOTHER EVER HAD A STROKE

DELETED

type: numeric (float)
label: HXEVHSGM

range: [1,3] units: 1
unique values: 3 coded missing: 1824 / 3106

tabulation:	Freq.	Numeric	Label
	1121	1	NO
	152	2	YES
	9	3	N/A

HXEVHSGM:
1. Required only if HXVERS='K'

HXEVHSGF ----- 91F HAS GRANDFATHER EVER HAD A STROKE

DELETED

type: numeric (float)
label: HXEVHSGF

range: [1,3] units: 1
unique values: 3 coded missing: 1827 / 3106

tabulation:	Freq.	Numeric	Label
	1178	1	NO
	85	2	YES
	16	3	N/A

HXEVHSGF:
1. Required only if HXVERS='K'

CALCULATED VARIABLE - HXEVHA: FAMILY HISTORY OF ASTHMA
SEE PAGES 1-8

HXEHAM ----- 92A HAS MOTHER EVER HAD ASTHMA

type: numeric (float)
label: HXEHAM
range: [1,3] units: 1
unique values: 3 coded missing: 1882 / 3106

tabulation:	Freq.	Numeric	Label
	1135	1	NO
	86	2	YES
	3	3	N/A

HXEHAM:

1. Required only if HXVERS='K'

CALCULATED VARIABLE - HXEVHA: FAMILY HISTORY OF ASTHMA
SEE PAGES 1-8

HXEVHAF ----- 92B HAS FATHER EVER HAD ASTHMA

type: numeric (float)
label: HXEVHAF
range: [1,3] units: 1
unique values: 3 coded missing: 1885 / 3106

tabulation:	Freq.	Numeric	Label
	1168	1	NO
	46	2	YES
	7	3	N/A

HXEVHAF:

1. Required only if HXVERS='K'

CALCULATED VARIABLE - HXEVHA: FAMILY HISTORY OF ASTHMA
SEE PAGES 1-8

HXEVHAS ----- 92C HAS SISTER EVER HAD ASTHMA

type: numeric (float)
label: HXEVHAS
range: [1,3] units: 1
unique values: 3 coded missing: 1882 / 3106

tabulation:	Freq.	Numeric	Label
	992	1	NO
	66	2	YES
	166	3	N/A

HXEVHAS:

1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 3
CSSCD INFANT COHORT PATIENTS

CALCULATED VARIABLE - HXEVHA: FAMILY HISTORY OF ASTHMA
SEE PAGES 1-8

HXEVHAB ----- 92D HAS BROTHER EVER HAD ASTHMA

type: numeric (float)
label: HXEVHAB
range: [1,3] units: 1
unique values: 3 coded missing: 1882 / 3106

tabulation:	Freq.	Numeric	Label
	979	1	NO
	79	2	YES
	166	3	N/A

HXEVHAB:

1. Required only if HXVERS='K'

HXENUR ----- 101 PT CURRENTLY HAVE PROBLEM W/ENURESIS

type: numeric (float)
label: HXENUR
range: [1,2] units: 1
unique values: 2 coded missing: 1878 / 3106

tabulation:	Freq.	Numeric	Label
	992	1	NO
	236	2	YES

HXENUR:

1. Required only if HXVERS='K'

HXENURN ----- 1011 # NIGHTS/MONTH EXPERIENCES ENURESIS

type: numeric (float)
label: HXENURN
range: [1,5] units: 1
unique values: 5 coded missing: 2876 / 3106

tabulation:	Freq.	Numeric	Label
	27	1	<1 NIGHT PER MONTH
	73	2	1-7 NIGHTS PER MONTH
	22	3	8-14 NIGHTS PER MONTH
	26	4	15-21 NIGHTS PER MONTH
	82	5	>21 NIGHT PER MONTH

HXENURN:

1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 3

CSSCD INFANT COHORT PATIENTS

HXGETUP ----- 102 PT GETS UP DURING NIGHT TO URINATE

type: numeric (float)
label: HXGETUP

range: [1,2] units: 1
unique values: 2 coded missing: 1882 / 3106

tabulation:	Freq.	Numeric	Label
	391	1	NO
	833	2	YES

HXGETUP:

1. Required only if HXVERS='K'

HXGETUPN ----- 1021 # NIGHTS/MONTH GETS UP TO URINATE

type: numeric (float)
label: HXGETUPN

range: [1,5] units: 1
unique values: 5 coded missing: 2277 / 3106

tabulation:	Freq.	Numeric	Label
	51	1	<1 NIGHT PER MONTH
	192	2	1-7 NIGHTS PER MONTH
	127	3	8-14 NIGHTS PER MONTH
	69	4	15-21 NIGHTS PER MONTH
	390	5	>21 NIGHT PER MONTH

HXGETUPN:

1. Required only if HXGETUP=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 4

CSSCD INFANT COHORT PATIENTS

HXDIFBR ----- 11 HAVE DIFFICULTY BREATHING WHEN ASLEEP

type: numeric (float)
label: HXDIFBR

range: [1,4] units: 1
unique values: 4 coded missing: 1881 / 3106

tabulation:	Freq.	Numeric	Label
	1094	1	NEVER
	105	2	OCCASIONALLY
	17	3	FREQUENTLY
	9	4	ALWAYS

HXDIFBR:

1. Required only if HXVERS='K'

HXSNORE ----- 12 DOES PATIENT SNORE

type: numeric (float)
label: HXSNORE

range: [1,4] units: 1
unique values: 4 coded missing: 1849 / 3106

tabulation:	Freq.	Numeric	Label
	523	1	NEVER
	468	2	OCCASIONALLY
	111	3	FREQUENTLY
	155	4	ALWAYS

HXSNORE:

1. Required only if HXVERS='K'

HXSTBR ----- 13 PT EVER STOP BREATHING WHILE SLEEPING

type: numeric (float)
label: HXSTBR

range: [1,4] units: 1
unique values: 4 coded missing: 1824 / 3106

tabulation:	Freq.	Numeric	Label
	1246	1	NEVER
	33	2	OCCASIONALLY
	2	3	FREQUENTLY
	1	4	ALWAYS

HXSTBR:

1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 4
 CSSCD INFANT COHORT PATIENTS

HXMPER ----- 14 PT BEGUN PERIOD SINCE LAST STDY VISIT

type: numeric (float)
 label: HXMPER
 range: [1,2] units: 1
 unique values: 2 coded missing: 2020 / 3106

tabulation:	Freq.	Numeric	Label
	949	1	NO
	137	2	YES

HXMPER:

1. Required only if SEX=1 and age >= 8 years

HXPREG ----- 15 HAS PATIENT EVER BEEN PREGNANT

DELETED

type: numeric (float)
 label: HXPREG
 range: [1,2] units: 1
 unique values: 2 coded missing: 2077 / 3106

tabulation:	Freq.	Numeric	Label
	1009	1	NO
	20	2	YES

HXPREG:

1. Required only if SEX=1 and age >= 8 years

HXPREGN ----- 151 IS PATIENT PREGNANT NOW

DELETED

type: numeric (float)
 label: HXPREGN
 range: [1,2] units: 1
 unique values: 2 coded missing: 3087 / 3106

tabulation:	Freq.	Numeric	Label
	13	1	NO
	6	2	YES

HXPREGN:

1. Required only if HXPREG=2 and HXVERS='K'

HXSCH ----- 16 IS PATIENT ENROLLED IN SCHOOL

type: numeric (float)
 label: HXSCH
 range: [1,2] units: 1
 unique values: 2 coded missing: 4 / 3106

tabulation:	Freq.	Numeric	Label
	510	1	NO
	2592	2	YES

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 4
 CSSCD INFANT COHORT PATIENTS

HXSCHLG ----- 161 LAST GRADE COMPLETED BY PATIENT

type: numeric (float)
 range: [0,13] units: 1
 unique values: 14 coded missing: 537 / 3106

tabulation:

Freq.	Value	Freq.	Value
206	0	182	7
321	1	140	8
306	2	106	9
343	3	57	10
317	4	40	11
291	5	15	12
243	6	2	13

HXSCHLG:

1. Required only if HXSCH=2

HXREPGR ----- 162 HAS PATIENT EVER REPEATED A GRADE

type: numeric (float)
 label: HXREPGR
 range: [1,2] units: 1
 unique values: 2 coded missing: 680 / 3106

tabulation:

Freq.	Numeric	Label
1866	1	NO
560	2	YES

HXREPGR:

1. Required only if HXSCHLG > 0

HXGRREP ----- 163 WHICH GRADE REPEATED

DELETED

type: numeric (float)
 range: [0,12] units: 1
 unique values: 13 coded missing: 2557 / 3106

tabulation:

Freq.	Value	Freq.	Value
22	0	24	6
151	1	15	7
122	2	7	8
105	3	13	9
59	4	5	10
23	5	2	11
		1	12

HXGRREP:

1. Required only if HXREPGR=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 5
CSSCD INFANT COHORT PATIENTS

HXWALK ----- 17 PT ABLE TO WALK UP 5 STEPS W/OUT HELP

type: numeric (float)
label: HXWALK

range: [1,8] units: 1
unique values: 3 coded missing: 1 / 3106

tabulation:	Freq.	Numeric	Label
	103	1	NO
	2999	2	YES
	3	8	N/A-TOO YOUNG

**CALCULATED VARIABLE - HXNOWALK:
ASSISTANCE NEEDED TO GET AROUND SEE PAGES 1-8**

HXWHEEL ----- 18A PT USE WHEELCHAIR TO GET AROUND

type: numeric (float)
label: HXWHEEL

range: [1,2] units: 1
unique values: 2 coded missing: 23 / 3106

tabulation:	Freq.	Numeric	Label
	3076	1	NO
	7	2	YES

**CALCULATED VARIABLE - HXNOWALK:
ASSISTANCE NEEDED TO GET AROUND SEE PAGES 1-8**

HXWALKR ----- 18B PT USE WALKER TO GET AROUND

type: numeric (float)
label: HXWALKR

range: [1,2] units: 1
unique values: 2 coded missing: 22 / 3106

tabulation:	Freq.	Numeric	Label
	3081	1	NO
	3	2	YES

**CALCULATED VARIABLE - HXNOWALK:
ASSISTANCE NEEDED TO GET AROUND SEE PAGES 1-8**

HXLEGBR ----- 18C PT USE LEG BRACE TO GET AROUND

type: numeric (float)
label: HXLEGBR

range: [1,2] units: 1
unique values: 2 coded missing: 23 / 3106

tabulation:	Freq.	Numeric	Label
	3059	1	NO
	24	2	YES

CALCULATED VARIABLE - HXNOWALK:
ASSISTANCE NEEDED TO GET AROUND SEE PAGES 1-8

HXCRTCH ----- 18D PT USE CRUTCHES TO GET AROUND

type: numeric (float)
label: HXCRTCH

range: [1,2] units: 1
unique values: 2 coded missing: 23 / 3106

tabulation:	Freq.	Numeric	Label
	3073	1	NO
	10	2	YES

CALCULATED VARIABLE - HXNOWALK:
ASSISTANCE NEEDED TO GET AROUND SEE PAGES 1-8

HXOTHW ----- 18E PT USE OTHER TO GET AROUND

type: numeric (float)
label: HXOTHW

range: [1,2] units: 1
unique values: 2 coded missing: 23 / 3106

tabulation:	Freq.	Numeric	Label
	3076	1	NO
	7	2	YES

HXOTHWT ----- 181 OTHER SPECIFY **DELETED**

type: string (str25)

unique values: 8 coded missing: 0 / 3106

tabulation:	Freq.	Value
	1	."
	3099	"C"
	1	"CANE"
	1	"CARRIED"
	1	"HAND AST"
	1	"HANDS ON"
	1	"MOTHER"
	1	"PEOPLE"

HXOTHWT:
1. Required only if HXOTHW=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 5
CSSCD INFANT COHORT PATIENTS

HXHSENUM ----- 19 # PEOPLE LIVE IN PTS HOUSE BESIDES PT

GROUPED

type: numeric (float)

SEE PAGES 1-8

range: [1,14] units: 1
unique values: 13 coded missing: 11 / 3106

tabulation:

Freq.	Value	Freq.	Value
229	1	105	7
694	2	70	8
794	3	28	9
562	4	8	10
407	5	5	11
189	6	2	13
		2	14

HXMOTHER ----- 191A # MOTHER/STEPMOTHER

type: numeric (float)

range: [0,1] units: 1
unique values: 2 coded missing: 9 / 3106

tabulation: Freq. Value
209 0
2888 1

HXFATHER ----- 191B # FATHER/STEPFATHER

type: numeric (float)

range: [0,1] units: 1
unique values: 2 coded missing: 9 / 3106

tabulation: Freq. Value
1745 0
1352 1

HXSYS ----- 191C # SISTERS/STEPSISTERS

GROUPED

type: numeric (float)

SEE PAGES 1-8

range: [0,6] units: 1
unique values: 7 coded missing: 8 / 3106

tabulation: Freq. Value
1417 0
1125 1
381 2
141 3
20 4
8 5
6 6

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 5
CSSCD INFANT COHORT PATIENTS

HXBRO ----- 191D # BROTHERS/STEPBROTHERS **GROUPED**
SEE PAGES 1-8

type: numeric (float)
range: [0,6] units: 1
unique values: 7 coded missing: 8 / 3106

tabulation:	Freq.	Value
	1440	0
	1102	1
	374	2
	105	3
	52	4
	23	5
	2	6

HX0THF1 ----- 191E # OTHER FEMALE RELATIVES **GROUPED**
SEE PAGES 1-8

type: numeric (float)
range: [0,8] units: 1
unique values: 8 coded missing: 8 / 3106

tabulation:	Freq.	Value
	2374	0
	477	1
	152	2
	59	3
	26	4
	6	5
	3	6
	1	8

HX0THM1 ----- 191F # OTHER MALE RELATIVES **GROUPED**
SEE PAGES 1-8

type: numeric (float)
range: [0,5] units: 1
unique values: 6 coded missing: 8 / 3106

tabulation:	Freq.	Value
	2645	0
	337	1
	74	2
	25	3
	15	4
	2	5

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 5
CSSCD INFANT COHORT PATIENTS

HX0THF2 ----- 191G # OTHER UNRELATED FEMALES **GROUPED**
SEE PAGES 1-8

type: numeric (float)
range: [0,3] units: 1
unique values: 4 coded missing: 8 / 3106

tabulation: Freq. Value
3039 0
44 1
9 2
6 3

HX0THM2 ----- 191H # OTHER UNRELATED MALES **GROUPED**
SEE PAGES 1-8

type: numeric (float)
range: [0,12] units: 1
unique values: 8 coded missing: 8 / 3106

tabulation: Freq. Value
3020 0
63 1
5 2
4 3
2 4
2 5
1 6
1 12

HXHSETOT ----- 191I TOTAL NUMBER **GROUPED**
SEE PAGES 1-8

type: numeric (float)
range: [1,14] units: 1
unique values: 13 coded missing: 11 / 3106

tabulation: Freq. Value
229 1
694 2
794 3
562 4
407 5
189 6
105 7
70 8
28 9
8 10
5 11
2 13
2 14

HXHSETOT:
1. HXHSETOT should equal HXHSENUM

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 6
 CSSCD INFANT COHORT PATIENTS

HXANINC ----- 20 HOUSEHOLDS TOTAL ANNUAL INCOME

GROUPED
SEE PAGES 1-8

type: numeric (float)
 label: HXANINC
 range: [1,99] units: 1
 unique values: 11 coded missing: 432 / 3106

tabulation:	Freq.	Numeric	Label
	296	1	LESS THAN \$5,000
	523	2	\$5,000 - \$9,999
	380	3	\$10,000 - \$14,999
	270	4	\$15,000 - \$19,999
	292	5	\$20,000 - \$29,999
	292	6	\$30,000 - \$49,999
	91	7	\$50,000 - \$69,999
	29	8	\$70,000 - \$99,999
	13	9	\$100,000 OR MORE
	205	77	REFUSED TO ANSWER
	283	99	DO NOT KNOW

HXANINC:
 1. Required only if HXVERS='G', 'E', or 'K'

HXPST1 ----- 21 EXTENT SCD AFFECTED PTS LIFE IN 6 MOS

type: numeric (float)
 label: HXPST1
 range: [1,5] units: 1
 unique values: 5 coded missing: 7 / 3106

tabulation:	Freq.	Numeric	Label
	887	1	NO SYMPTOMS
	1524	2	MINOR SYMPTOMS
	517	3	MILD SYMPTOMS
	136	4	MODERATE SYMPTOMS
	35	5	SEVERE SYMPTOMS

HXPST1:
 1. Assessment by person interviewed (HXPIN)

HXPST2 ----- 22 OVERALL DEGREE OF DISABILITY IN 6 MOS

type: numeric (float)
 label: HXPST2
 range: [1,5] units: 1
 unique values: 5 coded missing: 5 / 3106

tabulation:	Freq.	Numeric	Label
	906	1	NO SYMPTOMS
	1547	2	MINOR SYMPTOMS
	522	3	MILD SYMPTOMS
	110	4	MODERATE SYMPTOMS
	16	5	SEVERE SYMPTOMS

HXPST2:
 1. Assessment by medical personnel

HXCMPULU ----- 23A PT EVER EXPERIENCED LEG ULCERS

type: numeric (float)
 label: HXCMPULU
 range: [1,2] units: 1
 unique values: 2 coded missing: 1821 / 3106

tabulation:	Freq.	Numeric	Label
	1280	1	NO
	5	2	YES

HXCMPULU: 1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 6

CSSCD INFANT COHORT PATIENTS

HXCMPANH ----- 23B PT EVER EXPER ASEPTIC NECROSIS-HIP

type: numeric (float)
label: HXCMPANH
range: [1,2] units: 1
unique values: 2 coded missing: 1820 / 3106

tabulation:	Freq.	Numeric	Label
	1266	1	NO
	20	2	YES

HXCMPANH:

1. Required only if HXVERS='K'

HXCMPANS ----- 23C PT EVER EXPER ASEPTIC NECRO-SHOULDER

type: numeric (float)
label: HXCMPANS
range: [1,2] units: 1
unique values: 2 coded missing: 1820 / 3106

tabulation:	Freq.	Numeric	Label
	1284	1	NO
	2	2	YES

HXCMPANS:

1. Required only if HXVERS='K'

HXCMPSCR ----- 23D PT EVER EXPER SC RETINOPATHY

type: numeric (float)
label: HXCMPSCR
range: [1,2] units: 1
unique values: 2 coded missing: 1820 / 3106

tabulation:	Freq.	Numeric	Label
	1275	1	NO
	11	2	YES

HXCMPSCR:

1. Required only if HXVERS='K'

HXCTRN ----- 24 IS PT CURRENTLY ON A CHRONIC TX PROG

type: numeric (float)
label: HXCTRN
range: [1,2] units: 1
unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	2944	1	NO
	162	2	YES

HXCTRNLV ----- 241 IS THIS NEW SINCE LAST STUDY VISIT

type: numeric (float)
label: HXCTRNLV
range: [1,2] units: 1
unique values: 2 coded missing: 2944 / 3106

tabulation:	Freq.	Numeric	Label
	134	1	NO
	28	2	YES

HXCTRNLV: 1. Required only if HXCTRN=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 7

CSSCD INFANT COHORT PATIENTS

HXCTRNCV ----- 242A INDICATION-STROKE

type: numeric (float)
label: HXCTRNCV
range: [1,2] units: 1
unique values: 2 coded missing: 2945 / 3106

tabulation:	Freq.	Numeric	Label
	27	1	NO
	134	2	YES

HXCTRNCV:

1. Required only if HXCTRN=2

HXCTRPN ----- 242B INDICATION-RECURRENT PAIN EPISODES

type: numeric (float)
label: HXCTRPN
range: [1,2] units: 1
unique values: 2 coded missing: 2945 / 3106

tabulation:	Freq.	Numeric	Label
	157	1	NO
	4	2	YES

HXCTRPN:

1. Required only if HXCTRN=2

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 7

CSSCD INFANT COHORT PATIENTS

HXCTRNO ----- 242C INDICATION-OTHER

type: numeric (float)
label: HXCTRNO

range: [1,2] units: 1
unique values: 2 coded missing: 2945 / 3106

tabulation:	Freq.	Numeric	Label
	134	1	NO
	27	2	YES

HXCTRNO: 1. Required only if HXCTRNO=2

HXCTRNOT ----- 242C1 OTHER REASON FOR TX SPECIFY

type: string (str25)

unique values: 23 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
3079	"C"	1	"POSITIVE TCD"
1	"ABNORMAL MRI"	1	"PREVENTION OF CVA"
1	"ABNORMAL TCD"	1	"PRIAPISM"
2	"ACS"	1	"PUL FIBROSIS"
1	"ACUTE CHEST"	1	"PULMONARY HYPERTENSION"
2	"BRAIN INFARCT"	1	"RESP. FAILURE"
1	"BRAIN INFARCTS"	1	"SEIZURES"
3	"INFARCT W/HORNER SYNDROME"	1	"SEVERE ACCHEST"
1	"INFARCT/HORNERS SYND"	1	"STOP - ABN TCD"
1	"LUNG DISEASE"	1	"STOP PROTOCOL"
1	"LUNG DISEASE S/P ARDS"	2	"STOP STUDY"
		1	"STROKE PREVENTION"

HXCTRNOT: 1. Required only if HXCTRNO=2

HXASTH ----- 251A PT CARRY DX OF ASTHMA

type: numeric (float)
label: HXASTH

range: [1,2] units: 1
unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	2876	1	NO
	230	2	YES

HXCHRTF ----- 251B PT CARRY DX OF CHRON HEART DISEASE

type: numeric (float)
label: HXCHRTF

range: [1,2] units: 1
unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	3100	1	NO
	6	2	YES

HXCHRTF:

1. Wording on HXVERS='G' was 'Chronic Heart Failure'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 7

CSSCD INFANT COHORT PATIENTS

HXCHRTFT ----- 25B1 TYPE OF CHRON HEART DISEASE SPECIFY

type: string (str25)
unique values: 3 coded missing: 0 / 3106

tabulation: Freq. Value
 3103 "C"
 1 "CHF"
 2 "PULMONARY HYPERTENSION"

HXCHRTFT:

1. Required only if HXCHRTF=2 and HXVERS='K'

HXCHRTFC ----- CHRONIC HEART DISEASE ICD-9 CODE

type: numeric (float)
range: [416,428] units: 1
unique values: 2 coded missing: 3103 / 3106

tabulation: Freq. Value
 2 416
 1 428

HXCHRTFC:

1. Required only if HXCHRTF=2 and HXVERS='K'
2. See ICD-9 Codebook for disease codes

HXCLIVF ----- 251C PT CARRY DX OF CHRON LIVER DISEASE

type: numeric (float)
label: HXCLIVF
range: [1,2] units: 1
unique values: 2 coded missing: 0 / 3106

tabulation: Freq. Numeric Label
 3100 1 NO
 6 2 YES

HXCLIVF:

1. Wording on HXVERS='G' was 'Chronic Liver Failure'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 7

CSSCD INFANT COHORT PATIENTS

HXCLIVFT ----- 25C1 TYPE OF CHRON LIVER DISEASE SPECIFY

type: string (str25)
unique values: 4 coded missing: 0 / 3106

tabulation:	Freq.	Value
	3101	"C"
	2	"CHRONIC ACTIVE HEPATITIS"
	2	"HEPATITIS"
	1	"IRON OVERLOAD"

HXCLIVFT:

1. Required only if HXCLIVF=2 and HXVERS='K'

HXCLIVFC ----- CHRONIC LIVER DISEASE ICD-9 CODE

type: numeric (float)
range: [571.4,571.49] units: .01
unique values: 2 coded missing: 3103 / 3106

tabulation:	Freq.	Value
	2	571.4
	1	571.49

HXCLIVFC:

1. Required only if HXCLIVF=2 and HXVERS='K'
2. See ICD-9 codebook for disease codes

HXCREF ----- 251D PT CARRY DX OF CHRON RENAL DISEASE

type: numeric (float)
label: HXCREF
range: [1,2] units: 1
unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	3098	1	NO
	8	2	YES

HXCREF:

1. Wording on HXVERS='G' was 'Chronic Renal Failure'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 7
 CSSCD INFANT COHORT PATIENTS

HXCREFNT ----- 25D1 TYPE OF CHRON RENAL DISEASE SPECIFY
 type: string (str25)

unique values: 6 coded missing: 0 / 3106

tabulation:	Freq.	Value
	3099	"C"
	1	"FOCAL GLOMERULOSCLEROSIS"
	1	"HYDRONEPHROSIS"
	2	"NEPHROTIC SYNDROME"
	2	"RENAL FAILURE"
	1	"SCD NEPHROPATHY"

HXCREFNT:
 1. Required only if HXCREFN=2 and HXVERS='K'

HXCREFNC ----- CHRONIC RENAL DISEASE ICD-9 CODE
 type: numeric (float)

range: [581.1,591] units: .01
 unique values: 6 coded missing: 3099 / 3106

tabulation:	Freq.	Value
	1	581.1
	1	581.9
	1	582.1
	1	583.81
	2	585
	1	591

HXCREFNC:
 1. Required only if HXCREFN=2 and HXVERS='K'
 2. See ICD-9 codebook for disease codes

HXCREFND ----- 25D2 IS PATIENT RECEIVING DIALYSIS

DELETED

type: numeric (float)
 label: HXCREFND, but 1 value is not labeled

range: [1,1111] units: 1
 unique values: 2 coded missing: 3098 / 3106

tabulation:	Freq.	Numeric	Label
	7	1	NO
	1	2	YES

HXCREFND:
 1. Required only if HXCREFN=2 and HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 7
CSSCD INFANT COHORT PATIENTS

HXIRNOV ----- 251E PT CARRY DX OF IRON OVERLOAD

type: numeric (float)
label: HXIRNOV
range: [1,2] units: 1
unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	3027	1	NO
	79	2	YES

HXDIAB ----- 251F PT CARRY DX OF DIABETES

type: numeric (float)
label: HXDIAB
range: [1,1] units: 1
unique values: 1 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	3106	1	NO

HXRHFVEV ----- 251G PT CARRY DX OF RHEUMATIC FEVER

type: numeric (float)
label: HXRHFVEV
range: [1,1] units: 1
unique values: 1 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	3106	1	NO

HXTB ----- 251H PT CARRY DX OF TUBERCULOSIS

type: numeric (float)
label: HXTB
range: [1,1] units: 1
unique values: 1 coded missing: 1 / 3106

tabulation:	Freq.	Numeric	Label
	3105	1	NO

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 7

CSSCD INFANT COHORT PATIENTS

HXCANC ----- 251I PT CARRY DX OF CANCER

DELETED

type: numeric (float)
label: HXCANC
range: [1,2] units: 1
unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	3105	1	NO
	1	2	YES

HXCANCT ----- 251I1 TYPE OF CANCER SPECIFY

DELETED

type: string (str25)
unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Value
	3105	"C"
	1	"WILMS TUMOR"

HXCANCT:

1. Required only if HXCANC=2

HXCANCC ----- CANCER ICD-9 CODE

DELETED

type: numeric (float)
range: [189,189] units: 1
unique values: 1 coded missing: 3105 / 3106

tabulation:	Freq.	Value
	1	189

HXCANCC:

1. Required only if HXCANC=2
2. See ICD-9 codebook for disease codes

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 7

CSSCD INFANT COHORT PATIENTS

HXSEIZ ----- 251J PT CARRY DX OF SEIZURE

type: numeric (float)
label: HXSEIZ

range: [1,2] units: 1
unique values: 2 coded missing: 1 / 3106

tabulation:	Freq.	Numeric	Label
	3071	1	NO
	34	2	YES

HXHIVP ----- 251K PT CARRY DX OF HIV POSITIVITY

type: numeric (float)
label: HXHIVP

range: [1,1] units: 1
unique values: 1 coded missing: 1820 / 3106

tabulation:	Freq.	Numeric	Label
	1286	1	NO

HXHIVP:

1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 7

CSSCD INFANT COHORT PATIENTS

HXLDIS ----- 251L PT CARRY DX OF LEARNING DISABILITY

type: numeric (float)
label: HXLDIS

range: [1,2] units: 1
unique values: 2 coded missing: 1820 / 3106

tabulation:	Freq.	Numeric	Label
	1229	1	NO
	57	2	YES

HXLDIS:

1. Required only if HXVERS='K'

HXADD ----- 251M PT CARRY DX OF ATTENTION DEFICIT

type: numeric (float)
label: HXADD

range: [1,2] units: 1
unique values: 2 coded missing: 1821 / 3106

tabulation:	Freq.	Numeric	Label
	1266	1	NO
	19	2	YES

HXADD:

1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 8

CSSCD INFANT COHORT PATIENTS

HXDYSL ----- 251N PT CARRY DX OF DYSLEXIA

type: numeric (float)
label: HXDYSL

range: [1,2] units: 1
unique values: 2 coded missing: 1822 / 3106

tabulation:	Freq.	Numeric	Label
	1281	1	NO
	3	2	YES

HXDYSL:

1. Required only if HXVERS='K'

HXEPLL ----- 2510 PT CARRY DX OF ELEVATED BLOOD LEAD

type: numeric (float)
label: HXEPLL

range: [1,2] units: 1
unique values: 2 coded missing: 1879 / 3106

tabulation:	Freq.	Numeric	Label
	1216	1	NO
	11	2	YES

HXEPLL:

1. Defined as $\geq 10\mu\text{g/dL}$
2. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 8

CSSCD INFANT COHORT PATIENTS

HXTRSP ----- 251P PT CARRY DX S/P TRANSPLANTATION

DELETED

type: numeric (float)
label: HXTRSP

range: [1,2] units: 1
unique values: 2 coded missing: 1832 / 3106

tabulation:	Freq.	Numeric	Label
	1273	1	NO
	1	2	YES

HXTRSP:

1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 8

CSSCD INFANT COHORT PATIENTS

HXTRSPT ----- 25P1 ORGAN TRANSPLANTED

DELETED

type: string (str25)

unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Value
	3105	"C"
	1	"BONE MARROW"

HXTRSPT:

1. Required only if HXRSP=2

HXCDIS ----- 251Q PT CARRY DX OF OTHER CHRON DISEASE

type: numeric (float)

label: HXCDIS

range: [1,2]

units: 1

unique values: 2 coded missing: 0 / 3106

tabulation:	Freq.	Numeric	Label
	3069	1	NO
	37	2	YES

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PAGE 8
 CSSCD INFANT COHORT PATIENTS

HXCDIST ----- 25Q1 TYPE OF OTHER CHRONIC DISEASE

DELETED

type: string (str25)

unique values: 23

coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
3070	"C"	1	"G6PD DEFICIENCY"
1	"ALLERGIES/HAY FEVER"	1	"GRAFT VS HOST"
1	"ASEPT NECROSIS L HIP"	1	"HTN; MONO; NF"
1	"ASEPTIC NECROSIS"	1	"LUPUS"
1	"CAH"	2	"MYASTHENIA GRAVIS"
4	"CEREBRAL PALSY"	1	"NEUR DEFICIT S/P LOBECTMY"
1	"CHRON LUNG DXS/P ARDS"	1	"NEUROFIBROMATOSIS"
1	"CRPD"	2	"PULMONARY HTN"
2	"DEPRESSION"	1	"PULMONARY HYPERTENSION"
1	"ECZEMA/ALLERGIES"	1	"RECURRENT UTI"
1	"FAILURE TO THRIVE"	3	"RESTRICTIVE LUNG DZ"
		7	"TURNER'S SYNDROME"

HXCDIST:

1. Required only if HXCDIS=2

HXDISC ----- OTHER CHRONIC DISEASE ICD-9 CODE

DELETED

type: numeric (float)

range: [237.7,999.99]

units: .01

unique values: 21

coded missing: 3071 / 3106

tabulation:

Freq.	Value	Freq.	Value
1	237.7	1	571.49
2	311	1	599
4	343.9	1	692.9
2	358	1	710
1	401.9	1	733.4
2	416	1	733.42
1	416.8	7	758.6
3	518.89	1	781.9
1	518.9	1	783.4
1	519.9	1	996.85
		1	999.99

HXDISC:

1. Required only if HXCDIS=2
2. See ICD-9 codebook for disease codes

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 8

CSSCD INFANT COHORT PATIENTS

HXCORRL ----- 26 DOES PATIENT WEAR CORRECTIVE LENSES

type: numeric (float)
label: HXCORRL

range: [1,2] units: 1
unique values: 2 coded missing: 1839 / 3106

tabulation:	Freq.	Numeric	Label
	1001	1	NO
	266	2	YES

HXCORRL:

1. Required only if HXVERS='K'

HXHRAID ----- 27 DOES PATIENT USE A HEARING AID

DELETED

type: numeric (float)
label: HXHRAID

range: [1,3] units: 1
unique values: 3 coded missing: 1838 / 3106

tabulation:	Freq.	Numeric	Label
	1262	1	NO
	5	2	YES
	1	3	N/A PT DEAF

HXHRAID:

1. Required only if HXVERS='K'

HXFLUYR ----- 28 RCVD FLU VIRUS VACCINATION IN PAST YR

type: numeric (float)
label: HXFLUYR

range: [1,3] units: 1
unique values: 3 coded missing: 1884 / 3106

tabulation:	Freq.	Numeric	Label
	890	1	NO
	262	2	YES
	70	3	DOES NOT KNOW

HXFLUYR:

1. Required only if HXVERS='K'

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 8

CSSCD INFANT COHORT PATIENTS

HXFLU ----- 291A PT EVER RCVD H INFLUENZA VACCINE

type: numeric (float)
label: HXFLU

range: [1,9] units: 1
unique values: 3 coded missing: 40 / 3106

tabulation:	Freq.	Numeric	Label
	1616	1	NO
	1207	2	YES
	243	9	DOES NOT KNOW

HXPVNE ----- 292B PT EVER RCVD PNEUMOCOCCUS VACCINE

type: numeric (float)
label: HXPVNE

range: [1,9] units: 1
unique values: 3 coded missing: 41 / 3106

tabulation:	Freq.	Numeric	Label
	1355	1	NO
	1609	2	YES
	101	9	DOES NOT KNOW

HXVHEPB ----- 291C PT EVER RCVD HEPATITIS B VACCINE

type: numeric (float)
label: HXVHEPB

range: [1,9] units: 1
unique values: 3 coded missing: 43 / 3106

tabulation:	Freq.	Numeric	Label
	2077	1	NO
	800	2	YES
	186	9	DOES NOT KNOW

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM - PAGE 8

CSSCD INFANT COHORT PATIENTS

HXVMENIN ----- 291D PT EVER RCVD MENINGOCOCCUS VACCINE

type: numeric (float)
label: HXVMENIN
range: [1,9] units: 1
unique values: 3 coded missing: 51 / 3106

tabulation:	Freq.	Numeric	Label
	2894	1	NO
	19	2	YES
	142	9	DOES NOT KNOW

HXBSTAT ----- 30 IS PATIENT ON SPECIAL B STATUS

type: numeric (float)
label: HXBSTAT
range: [1,2] units: 1
unique values: 2 coded missing: 2 / 3106

tabulation:	Freq.	Numeric	Label
	3041	1	NO
	63	2	YES

HXTRSL ----- 31 TRANSLATOR NEEDED TO COMPLETE FORM

type: numeric (float)
label: HXTRSL
range: [1,2] units: 1
unique values: 2 coded missing: 1 / 3106

tabulation:	Freq.	Numeric	Label
	3045	1	NO
	60	2	YES

CODEBOOK FOR CSSCD FORM HXP

HISTORY FORM

CSSCD INFANT COHORT PATIENTS

HXTRNSC ----- DATA TRANSCRIBED FROM OLDER VERSION

type: numeric (float)
label: HXTRNSC

range: [1,2] units: 1
unique values: 2 coded missing: 1798 / 3106

tabulation:	Freq.	Numeric	Label
	1226	1	NO
	82	2	YES

HXTRNSC:

1. Required only if HXVERS='K'

HXOVERS ----- VERSION DATA TRANSCRIBED FROM

type: string (str2)

unique values: 5 coded missing: 4 / 3106

tabulation:	Freq.	Value
	3020	"-7"
	1	"A"
	20	"E"
	17	"H"
	44	"I"

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 1
CSSCD INFANT COHORT PATIENTS

HXPCARE ----- PERSON INTERVIEW PRIMARY CAREGIVER (PH2)

type: numeric (float)
label: HXPCARE

range: [1,2] units: 1
unique values: 2 coded missing: 1318 / 3106

tabulation:	Freq.	Numeric	Label
	85	1	NO
	1703	2	YES

HXPCARE: 1. Required only if HXVERS='G', 'A', or 'E'

HXRELP ----- RELATIONSHIP PRIM CAREGIVER TO PT (PH2)

DELETED

type: string (str12)

unique values: 15 coded missing: 0 / 3106

tabulation:	Freq.	Value
	5	"."
	3	"B"
	2995	"C"
	4	"AUNT"
	1	"COUNSELOR"
	2	"DAD GLFRIEND"
	1	"FAMLY FRIEND"
	4	"FATHER"
	7	"GRANDMOTHER"
	68	"MOTHER"
	9	"PARENT"
	1	"SELF"
	3	"SISTER"
	2	"STEPFATHER"
	1	"UNCLE"

HXRELP: 1. Required only if HXPCARE=1

HXMIRN ----- TAKING IRON (PH2)

type: numeric (float)
label: HXMIRN

range: [1,2] units: 1
unique values: 2 coded missing: 1705 / 3106

tabulation:	Freq.	Numeric	Label
	1399	1	NO
	2	2	YES

HXMIRN:
1. Required only if HXVERS='G', 'A', or 'E'

HXMIRNLV ----- IRON STARTED SINCE LAST STDY VISIT (PH2)

type: numeric (float)
label: HXMIRNLV

range: [1,2] units: 1
unique values: 2 coded missing: 3100 / 3106

tabulation:	Freq.	Numeric	Label
	3	1	NO
	3	2	YES

HXMIRNLV:
1. Required only if HXMIRN=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 1
CSSCD INFANT COHORT PATIENTS

HXMPROPS ----- TAKING RANDOMIZED DRUG FOR PROPS (PH2)

type: numeric (float)
label: HXMPROPS

range: [1,2] units: 1
unique values: 2 coded missing: 1708 / 3106

tabulation:	Freq.	Numeric	Label
	1165	1	NO
	233	2	YES

HXMPROPS:

1. Required only if HXVERS='G', 'A', or 'E'

HXMPRLV ----- PROPS STARTED SINCE LAST STDY VISIT(PH2)

type: numeric (float)
label: HXMPRLV

range: [1,2] units: 1
unique values: 2 coded missing: 2881 / 3106

tabulation:	Freq.	Numeric	Label
	201	1	NO
	24	2	YES

HXMPRLV:

1. Required only if HXMPROPS=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 1
CSSCD INFANT COHORT PATIENTS

HXRCHPRO ----- PARTICIP IN OTHR RESEARCH PROTOCOL (PH2)

type: numeric (float)
label: HXRCHPRO

range: [1,2] units: 1
unique values: 2 coded missing: 1309 / 3106

tabulation:	Freq.	Numeric	Label
	1380	1	NO
	417	2	YES

HXRCHPRO:

1. Required only if HXVERS='G', 'A', or 'E'

HXPROPS ----- IS PT PARTICIPATING IN PROPS2 (PH2)

type: numeric (float)
label: HXPROPS

range: [1,2] units: 1
unique values: 2 coded missing: 2689 / 3106

tabulation:	Freq.	Numeric	Label
	39	1	NO
	378	2	YES

HXPROPS:

1. Required only if HXRCHPRO=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 2
CSSCD INFANT COHORT PATIENTS

HXLIVS ----- PT TREATED FOR HEPATIC SEQUEST (PH2)

 type: numeric (float)
 label: HXLIVS

 range: [1,1] units: 1
unique values: 1 coded missing: 2946 / 3106

 tabulation: Freq. Numeric Label
 160 1 NO

HXLIVS:

1. Required only if HXVERS='G', 'A', or 'E'

HXLIVSN ----- # TIMES SEEN FOR HEPATIC SEQUEST (PH2)

 type: numeric (float)

 range: [.,.] units: .
unique values: 0 coded missing: 3106 / 3106

 tabulation: Freq. Value
 Value missing for all patients

HXLIVSN:

1. Required only if HXLIVS=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 3
 CSSCD INFANT COHORT PATIENTS

HXSCHDM ----- PAST 2 WK PT MISS WHOLE DAY SCHOOL (PH2)

type: numeric (float)
 label: HXSCHDM

range: [1,8] units: 1
 unique values: 3 coded missing: 1801 / 3106

tabulation:	Freq.	Numeric	Label
	799	1	NO
	380	2	YES
	126	8	N/A-SCHOOL NOT IN SESSION

HXSCHDM:

1. Required only if HXVERS='G', 'A', or 'E'

HXNSCHDM ----- # DIFFRENT WHOLE DAYS MISS SCHOOL (PH2)

type: numeric (float)

range: [1,14] units: 1
 unique values: 12 coded missing: 2726 / 3106

tabulation:

Freq.	Value	Freq.	Value
114	1	14	7
95	2	2	9
50	3	18	10
25	4	1	12
45	5	1	13
10	6	5	14

HXNSCHDM:

1. Required only if HXSCHDM=2

HXNSCHDH ----- # DUE TO PTS HEALTH RELATED PROBS (PH2)

type: numeric (float)

GROUPED
SEE PAGES 1-8

range: [0,14] units: 1
 unique values: 13 coded missing: 2727 / 3106

tabulation:

Freq.	Value	Freq.	Value
63	0	8	6
85	1	13	7
81	2	1	9
42	3	18	10
21	4	1	12
40	5	1	13
		5	14

HXNSCHDH:

1. Required only if HXSCHDM=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 3
 CSSCD INFANT COHORT PATIENTS

HXSCHDL ----- # DAYS ARRIVE LATE/LEAVE SCH EARLY (PH2)
 type: numeric (float)

range: [0,7] units: 1
 unique values: 8 coded missing: 1925 / 3106

tabulation:	Freq.	Value
	1114	0
	38	1
	13	2
	6	3
	2	4
	3	5
	2	6
	3	7

HXSCHDL: 1. Required only if HXVERS='G', 'A', or 'E'

HXSCHDIL ----- PAST 2 WKS PT ATTEND SCHOOL ILL (PH2)
 type: numeric (float)
 label: HXSCHDIL

range: [1,2] units: 1
 unique values: 2 coded missing: 1922 / 3106

tabulation:	Freq.	Numeric	Label
	1013	1	NO
	171	2	YES

HXSCHDIL: 1. Required only if HXVERS='G', 'A', or 'E'

HXNSCHDI ----- # DAYS ATTENDED SCHOOL ILL (PH2)
 type: numeric (float)

range: [0,14] units: 1
 unique values: 8 coded missing: 2936 / 3106

tabulation:	Freq.	Value
	1	0
	70	1
	45	2
	27	3
	13	4
	11	5
	2	6
	1	14

HXNSCHDI: 1. Required only if HXSCHDIL=2

HXTEASC ----- TEACHER KNOW PT HAS SICKLE CELL (PH2)
 type: numeric (float)
 label: HXTEASC

range: [1,2] units: 1
 unique values: 2 coded missing: 1908 / 3106

tabulation:	Freq.	Numeric	Label
	77	1	NO
	1121	2	YES

HXTEASC:
 1. Required only if HXVERS='G', 'A', or 'E'

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 3
 CSSCD INFANT COHORT PATIENTS

HXREC ----- PT ABLE TO PARTIC IN RECREATION (PH2)

type: numeric (float)
 label: HXREC

range: [1,8] units: 1
 unique values: 3 coded missing: 1310 / 3106

tabulation:	Freq.	Numeric	Label
	1481	1	NO
	271	2	YES
	44	8	N/A NO ACTIVITIES

HXREC:

1. Required only if HXVERS='G', 'A', or 'E'

HXRECD ----- # DAYS UNABLE TO PARTIC PAST 2 WKS (PH2)

type: numeric (float)

range: [0,14] units: 1
 unique values: 14 coded missing: 2848 / 3106

tabulation:	Freq.	Value
	2	0
	37	1
	55	2
	53	3
	13	4
	36	5
	9	6
	16	7
	5	8
	2	9
	17	10
	1	11
	1	12
	11	14

HXRECD:

1. Required only if HXREC=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 3
 CSSCD INFANT COHORT PATIENTS

HXRECLM ----- REASON FOR THIS LIMITATION (PH2)
 type: string (str20)

unique values: 156 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
8	". "	1	"FEVER & COUGH"
3	"B"	1	"FEVER + STROKE"
2846	"C"	1	"FEVER AND COLD"
1	"A COLD"	1	"FEVER COUGH SORE THR"
1	"ABD PAIN FEVER"	1	"FEVER; EAR INFECTION"
2	"ABD. PAIN"	1	"FEVER;LEG/CHSTCRISIS"
5	"ABDOMINAL PAIN"	1	"FEVERISH; ILL"
1	"ABDPAINANDHEADACHE"	1	"FLU"
1	"ABSENT FROM SCHOOL"	1	"FLU SYMPTOMS"
1	"ACS"	1	"FOOT&THROAT PAIN"
1	"APLASTIC CRISIS"	1	"FOREHEAD INJURY"
4	"ARM PAIN"	1	"FRACTURED PELVIC"
1	"ASTHMA"	2	"FULL BODY PAINCRISIS"
1	"ASTHMA + PAIN CRISIS"	1	"GYM CAUSES PAIN"
1	"BACK & STOMACH PAIN"	1	"HA & SORE THROAT"
2	"BACK PAIN"	1	"HA & STOMACHEACHE"
1	"BACK PAIN + FEVER"	1	"HE TIRES EASILY"
1	"BACK PAINS"	1	"HEAD COLD"
1	"BACKACHE"	3	"HEADACHE"
1	"BAD COLD"	1	"HEADACHE AND FEVER"
1	"BOM"	1	"HEADACHE; STOMACHE"
1	"BOTH LEGS PAIN"	1	"HEADACHES"
1	"BRACE"	1	"HIP PROBLEMS"
1	"CAR ACCIDENT INJURY"	1	"HOSP FOR NECK PAIN"
3	"CHEST PAIN"	1	"HOSP FOR PNEUMONIA"
4	"COLD"	1	"HOSP FOR VOC; FEVER"
1	"COLD & FEVER"	1	"HOSP. PYELONEPH./UTI"
1	"COLD-URI;L KNEE PAIN"	1	"HOSP. W/ PNEUMONIA"
1	"COLD/FLU"	1	"HOSPACUTECHST"
1	"COLD; FEVER"	2	"HOSPITALIZATION"
1	"COLD; VIRUS; FLU"	1	"HOSPITALIZATN: FEVER"
1	"CONSTIPATION"	5	"HOSPITALIZED"
1	"COUGH & HEADACHE"	1	"HOSPITALIZED - PAIN"
1	"COUGH (COLD)"	1	"HOSPITALIZED-CRISIS"
1	"COUGH AND BODY ACHE"	1	"HOSPITALIZED/PAIN"
1	"COUGH LOW BACK PAIN"	1	"ILL & IN HOSPITAL"
1	"COUGH;COLD;RUN NOSE"	7	"ILLNESS"
1	"CRISIS"	1	"IN HOSPITAL - FEVER"
1	"DIDN'T FEEL WELL"	1	"INJURY LEFT ELBOW"
1	"DIZZY/LOSS BALAN/HA"	1	"JOINT PAIN"
1	"DIZZY; ARM HURTING"	2	"KNEE PAIN"
2	"DON'T KNOW"	1	"L. ANKLE PAIN"
1	"EYES;TONSILS-SWOLLEN"	1	"LEG & STOMACH PAIN"
1	"FATIGUE"	1	"LEG + ARM PAIN"
1	"FATIGUE DUE LOW HGB"	6	"LEG PAIN"
1	"FELL OFF BIKE"	1	"LEG PAIN + ASTHMA"
5	"FEVER"	1	"LEG PAIN/SORE THROAT"

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 3
 CSSCD INFANT COHORT PATIENTS

HXRECLM(cont'd) ----- REASON FOR THIS LIMITATION (PH2)
 type: string (str20)

unique values: 156 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
1	"LEG PAIN; H/A; DIZZY"	1	"PRIAPISM"
1	"LEG SURGERY"	1	"RECENT GB SURGERY"
1	"LOM R. LIMBS"	1	"RT KNEE PAIN"
1	"MILD BODY ACHES/PAIN"	1	"S.C. RELATED PROBLEME"
1	"MILD SICKLE PAIN"	1	"S/P HEEL CORD LENGTH"
1	"MISCARRIAGE"	1	"SC CRISIS"
1	"NECK PAIN"	1	"SC ILLNESS"
2	"NOT FEELING WELL"	1	"SEPSIS/RENAL FAILURE"
1	"NOT STATED"	2	"SICK"
46	"PAIN"	1	"SICKLE CELL CRISIS"
1	"PAIN - LOWER BACK"	1	"SICKLE CELL PAIN"
1	"PAIN AND URI"	1	"SICKLE PAIN EVENT"
6	"PAIN CRISIS"	1	"SMASHED R INDEX FNGR"
1	"PAIN CRISIS & FEVER"	1	"SORE THROAT"
1	"PAIN CRISIS-LOW BACK"	1	"SORETHROAT"
1	"PAIN EPISODE LEGS"	1	"SPLENIC SEQUEST;HOSP"
1	"PAIN EPISODE; FEVER"	1	"SPRAINED ANKLE"
1	"PAIN IN HANDS"	1	"STOMACH PAIN"
1	"PAIN IN LEFT KNEE"	1	"STOMACH VIRUS"
4	"PAIN IN LEGS"	1	"STREP THROAT"
1	"PAIN IN LEGS & ABDOM"	1	"SURGERY"
1	"PAIN IN STOMACH"	1	"SWOLLEN ANKLE"
1	"PAIN L LEG"	1	"SWOLLEN FEET"
1	"PAIN RIGHT ARM"	1	"TIRED"
1	"PAIN/FEVER"	1	"TONSILLECTOMY"
1	"PAIN/SWELL FOOT/KNEE"	1	"TOO TIRED"
1	"PAIN/TEMP/SORE THRT"	1	"TRANSFUSION"
1	"PAIN; COLD"	3	"URI"
1	"PAINFUL EVENT"	1	"VIRAL INFECTION"
1	"PAINS IN LEGS"	1	"WEAKNESS"
1	"PNEUMONIA"	1	"WEAKNESS - RIGHT LEG"

HXRECLM:

1. Required only if HXREC=2

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 4
 CSSCD INFANT COHORT PATIENTS

HXHLTHY ----- HLTHY ENOUGH TO DO THINGS WANTS TO (PH2)

type: numeric (float)
 label: HXHLTHY

range: [1,5] units: 1
 unique values: 5 coded missing: 1316 / 3106

tabulation:	Freq.	Numeric	Label
	478	1	ALL OF THE TIME
	1089	2	MOST OF THE TIME
	219	3	SOME OF THE TIME
	3	4	ALMOST NEVER
	1	5	NEVER

HXHLTHY: 1. Required only if HXVERS='G', 'A', or 'E'

HXHLTH1 ----- RATE PTS HEALTH TO OTHERS SAME AGE (PH2)

type: numeric (float)
 label: HXHLTH1

range: [1,5] units: 1
 unique values: 5 coded missing: 1316 / 3106

tabulation:	Freq.	Numeric	Label
	168	1	MUCH BETTER
	295	2	SOMEWHAT BETTER
	871	3	SAME
	419	4	SOMEWHAT WORSE
	37	5	MUCH WORSE

HXHLTH1: 1. Required only if HXVERS='G', 'A', or 'E'

HXHLTH2 ----- RATE PTS HLTH TO OTHERS W/SC (PH2)

type: numeric (float)
 label: HXHLTH2

range: [1,5] units: 1
 unique values: 5 coded missing: 1363 / 3106

tabulation:	Freq.	Numeric	Label
	485	1	MUCH BETTER
	771	2	SOMEWHAT BETTER
	381	3	SAME
	99	4	SOMEWHAT WORSE
	7	5	MUCH WORSE

HXHLTH2: 1. Required only if HXVERS='G', 'A', or 'E'

HXHLTH3 ----- RATE SELF HLTH TO OTHERS SAME AGE (PH2)

type: numeric (float)
 label: HXHLTH3

range: [1,5] units: 1
 unique values: 5 coded missing: 1734 / 3106

tabulation:	Freq.	Numeric	Label
	142	1	MUCH BETTER
	233	2	SOMEWHAT BETTER
	791	3	SAME
	192	4	SOMEWHAT WORSE
	14	5	MUCH WORSE

HXHLTH3:
 1. Required only if (HXVERS='G', 'A', or 'E') and patient >= 6 years of age

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 5
CSSCD INFANT COHORT PATIENTS

HXPRINC ----- HOUSEHOLD PRIMARY SOURCE OF INCOME (PH2)

GROUPED
SEE PAGES 1-8

type: numeric (float)
label: HXPRINC
range: [1,99] units: 1
unique values: 12 coded missing: 1731 / 3106

tabulation:	Freq.	Numeric	Label
	28	1	SOCIAL SECURITY
	517	2	SSI OR WELFARE
	1	3	PRIVATE PENSION
	6	4	WORKERS COMP
	15	5	NOT DISAB BENEFITS
	5	7	GOV/VETERAN PENSION
	673	8	JOB OF PARENT/GUARDIAN
	49	9	OTH HOUSEHOLD CONTRIB
	5	10	NONHOUSEHOLD CONTRIB
	6	11	OTHER SOURCE
	53	77	REFUSED TO ANSWER
	17	99	DO NOT KNOW

HXPRINC:

1. Required only if HXVERS='G' or 'E'

HXOPRINC ----- OTHER SOURCE OF INCOME SPECIFY (PH2)

type: string (str15)
unique values: 5 coded missing: 0 / 3106

tabulation:	Freq.	Value
	3099	"C"
	1	"-7"
	4	"AFDC"
	1	"CHILD SUPPORT"
	1	"SELLING ITEMS"

HXOPRINC:

1. Required only if HXPRINC=11

CODEBOOK FOR CSSCD FORM HXP
 HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 5
 CSSCD INFANT COHORT PATIENTS

HXR1 ----- WAS TRTMENT RECOMMENDED AS RESULT (PH2)
 type: numeric (float)
 label: HXR1
 range: [1,2] units: 1
 unique values: 2 coded missing: 3046 / 3106

tabulation:	Freq.	Numeric	Label
	25	1	NO
	35	2	YES

HXR1:
 1. Required only if HXREF=2

HXR1T1 ----- SPECIFY RECOMMENDED TREATMENT 1 (PH2)
 type: string (str20)
 unique values: 33 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
1	."	1	"HERNIA REPAIR"
1	"A"	1	"HERNIA REPAIR/TRANSF"
3071	"C"	1	"HOSP FOR CHELATION"
1	"BRACE ON LEG"	1	"HYDRALAZINE"
1	"BRAIN SCAN & MRI"	1	"IBUPROFEN"
1	"CHLORANYCHENICOL"	1	"INDERAL"
1	"CHOLECYSTECTOMY"	1	"LESIONS EXCISED"
1	"CHRONIC TXN PROGRAM"	1	"ORAL STEROIDS"
1	"CORRECTIVE GLASSES"	2	"PSYCHOTHERAPY"
1	"COUNSELING"	1	"SCHEDULED MRI"
1	"CRUTCH WALKING"	1	"SHORT TERM DIALYSIS"
1	"DONNATAL ELIXIN"	1	"SPEECH THERAPY"
1	"EMBOLIZE THE LESION"	1	"SPLENECTOMY"
1	"ENT REFERRAL MADE"	1	"SURGERY SCHEDULE"
3	"GLASSES"	1	"SUTURES TO FINGER"
1	"GLASSES/TONSILLECTMY"	1	"T & A"
		1	"TRANSFUSION THERAPY"

HXR1T1:
 1. Required only if HXR1=2

HXT2 ----- ADDITIONAL TEST 2 (PH2)
 type: string (str20)
 unique values: 21 coded missing: 0 / 3106

tabulation:

Freq.	Value	Freq.	Value
1	."	1	"MRI"
3084	"C"	1	"MRI-PELVIS"
1	"ABD/RENAL U/S"	3	"NEUROLOGIST"
1	"ARTERIOGRAM"	1	"ORTHOPEDIC"
1	"BLOOD CHEMISTRY"	1	"REHAB"
1	"DEVELOPMENTAL DELAY"	1	"REHABILITATION"
1	"ENT"	1	"S/I RUS"
1	"GALLBLADDER USG"	1	"SICKLE EYE EXAM"
1	"GENETIC"	1	"SPEECH"
1	"KIDNEY PROFILE"	1	"VCUG"

HXT2:
 1. Required only if HXREF=2 and more than one referral

CODEBOOK FOR CSSCD FORM HXP
 HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 5
 CSSCD INFANT COHORT PATIENTS

HXOUT2 ----- OUTCOME TEST 2 (PH2)

type: numeric (float)
 label: HXOUT2

range: [1,2] units: 1
 unique values: 2 coded missing: 3094 / 3106

tabulation:	Freq.	Numeric	Label
	6	1	NORMAL
	6	2	ABNORMAL

HXOUT2:

1. Required only if HXREF=2 and more than one referral

HXR2 ----- WAS TRTMENT RECOMMENDED AS RESULT (PH2)

type: numeric (float)
 label: HXR2

range: [1,2] units: 1
 unique values: 2 coded missing: 3094 / 3106

tabulation:	Freq.	Numeric	Label
	7	1	NO
	5	2	YES

HXR2:

1. Required only if HXREF=2 and more than one referral

HXR2T ----- SPECIFY RECOMMENDED TREATMENT 2 (PH2)

type: string (str20)

unique values: 7 coded missing: 0 / 3106

tabulation:	Freq.	Value
	3100	"C"
	1	"CRUTCH WALKING"
	1	"LAP. CHOLECYSTECTOMY"
	1	"MOM STIMULATE VERBAL"
	1	"OCCUP.+PHYS. THERAPY"
	1	"PT FAILED APPT."
	1	"STRENGTHEN EXERCISES"

HXR2T:

1. Required only if HXR2=2

HXT3 ----- ADDITIONAL TEST 3 (PH2)

type: string (str20)

unique values: 6 coded missing: 0 / 3106

tabulation:	Freq.	Value
	1	."
	3101	"C"
	1	"ARTERIOGRAM"
	1	"CAROTID DOP & ANGIOG"
	1	"LIVER PROFILE"
	1	"URINE"

HXT3:

1. Required only if HXREF=2 and more than one referral

CODEBOOK FOR CSSCD FORM HXP
HISTORY FORM - PHASE 2 ENTRY/ANNUAL ONLY - PAGE 5
CSSCD INFANT COHORT PATIENTS

HXOUT3 ----- OUTCOME TEST 3 (PH2)

type: numeric (float)
label: HXOUT3

range: [1,1] units: 1
unique values: 1 coded missing: 3103 / 3106

tabulation:	Freq.	Numeric	Label
	3	1	NORMAL

HXOUT3:

1. Required only if HXREF=2 and more than one referral

HXR3 ----- WAS TRTMENT RECOMMENDED AS RESULT (PH2)

type: numeric (float)
label: HXR3

range: [1,1] units: 1
unique values: 1 coded missing: 3104 / 3106

tabulation:	Freq.	Numeric	Label
	2	1	NO

HXR3:

1. Required only if HXREF=2 and more than one referral

HXR3T3 ----- SPECIFY RECOMMENDED TREATMENT 3 (PH2)

type: string (str20)

unique values: 1 coded missing: 0 / 3106

tabulation:	Freq.	Value
	3106	"C"

HXR3T3:

1. Required only if HXR3=2

_dta:

1. Codebook created 02/11/2000