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## 1.0: Patient Roster (Case) Information – “Record” 9

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- **ANONID** – is an 8-digit variable defined as a character string. In the SAS dataset, this variable replaces **CASEID** which was derived by concatenating 3 other variables: **CLINIC**, **HSEHOLD**, and **LINENO**. The first 2 digits of **CASEID** were clinic # that the patient was last followed at; the next 4 digits were the household # of the patient which was assigned by the clinic, and the last 2 digits were the position # of the patient within the household. The position # is the line # on Form 1 which contains the following information for the entered patient: relationship to the head of the household, sex, and birthdate. The variables **CLINIC** and **HOUSEHOLD** have been dropped from the dataset sent to NIH.
- **BIRTHDAY** – is the variable name for date of birth. The source of the information for the date was FORM #1 (Household Enumeration Form) or, less frequently, Form #2 (Patient Demographic Form).
- **CLINICL** – is an anonymized letter code identifying the clinical center at which the patient was last being followed.
- **DOE** – is the variable name for date of study entry. For the majority of patients entered at  $\geq 2$  years of age, **DOE** should be equal to the date of the physical exam (**F11DATE**) reported on the Intake Physical Exam form (Form 11). For patients who were pregnant at entry, the Pregnancy Form (Form 82) served as the entry physical exam form and **DOE** should correspond to the date on the first pregnancy form (Form 82, **F82DATE**) on the database.

For patients entered at  $< 2$  years of age, **DOE** will be equal to the date of the first Infant Interim Clinic Visit form on the database (Form 16, **F16DATE**) or the first Extension Infant Interim Clinic Visit form on the database (Form 16E, **F24DATE**). The Infant Interim Clinic Visit form was used between 03/79 and 03/84. The Extension Infant Interim Clinic Visit form was used between 03/84 and 10/88.

The Phase 1 enrollment period for patients over the age of 6 months was between 3/79 and 5/81. Enrollment of patients less than 6 months of age continued through 9/88. However, enrollment of infants was optional after May 1986.

- **DXSOURCE** – is the variable name for the source of the local hemoglobin diagnosis (see **HEMO2**).

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- **ELIGIBLE** – is the variable name for whether an SCD newborn was eligible for control matching. In general, 2 HbA controls were to be entered for each SCD infant entered at < 5\* months of age before November 1982. **R09.SD2** and **R14.SD2** contain the variables needed to determine eligibility status (**BIRTHDAY**, **SEX**, **RACE** in **R09.SD2**; **F14GSAGE**, **F14TYPDL**, **F14APGR5**, **F14WGT** in **R14.SD2**).

All SCD newborns (patients entered at < 5\* months of age) who were entered in the study before November 1982 were to be matched with 2 HbA controls *except* for

1. those with congenital defects
2. those delivered by primary caesarian sections or secondary caesarian sections with problems
3. those born weighing less than 2200 grams
4. those with 5-minute apgar scores under 5
5. those with gestational age < 37 weeks or > 41 weeks

The criteria used in selecting the 2 matched AA controls from a clinic-affiliated hospital or outpatient clinic were as follows:

The control infant should

1. have a Hb electrophoresis pattern of FA
2. not have any overt congenital defects
3. not have been delivered by C-section except by repeat C-section with no problems
4. have a birthdate within 6 months following the birthdate of the SCD newborn
5. be of the same race
6. have a gestational age within the 37-41 week range
7. be of the same sex
8. have a birth weight within 500 grams of the SCD infant if the SCD infant weighed 2200 grams or more
9. have a 5-minute apgar score within 1 of that of the SCD infant if the apgar score of the SCD infant was 6 or greater. An apgar score of 5 could only be matched with scores of 5 or 6.

Controls who met all matching criteria were to be contacted for participation in order of the closest time of birth to the SCD infant until 2 agreed to participate and

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the entry age of the control was < 6 months of age. Follow-up of controls was discontinued in November 1983.

\* Note: Newborns were originally defined as those entered at < 5 months of age; in November 1986, the definition was changed to include all patients entered at < 6 months of age.

- **FAMID2** – is the variable name for the anonymized family ID # which is an 8-digit character string. In households with more than 1 study participant, the **ANONID** # of one of the participants was selected as the family ID # for all participating household members. In households with only 1 study participant, **FAMID2=ANONID**.
- **HASTUBE** – is the variable name for whether or not a DNA sample is stored at the CSSCD Specimen Repository (BBI-Biotech Research Laboratories in Gaithersburg, MD). DNA samples were NOT required for patients with a diagnosis of HbSC or HbS/β<sup>+</sup> thalassemia (**HEMO**=2 or 3 respectively).
- **HEMO** – is the variable name for hemoglobinopathy. The CDC performed cellulose acetate hemoglobin electrophoresis and quantitative chromatography for each patient (usually at entry). Diagnoses of hemoglobinopathies were assigned according to the following hemoglobin patterns: SS disease-S, F, A2 (< 4%); SC disease-S, C; S/β<sup>+</sup> thalassemia-S, F, A, A2; and S/β<sup>0</sup> thalassemia-S, F, A2 (≥ 4%). For patients entered at < 2 years of age, a repeat hemoglobin electrophoresis by the CDC at age ≥ 2 years was required to confirm the early diagnosis. CDC hemoglobin electrophoresis results are stored in **R06.SD2**. In addition, 1) globin chain biosynthesis studies (**R06.SD2** variable: **RATIO**) were done on a small number of patients, 2) Kleihaur-Betke stains (**R06.SD2** variables: **AESCLIN**, **AESQUAL**) were done on a small number of patients, 3) alpha gene mapping was done on the majority of HbSS patients (**R04.SD2** variable: **F04ALPHA**), and 4) family study reports were reviewed if available. Depending on the results of these additional studies and/or review by the Laboratory Committee Chairman (Dr. Martin Steinberg), one of the following **HEMO** values was assigned:
  1. HbSS (includes unmapped as well as mapped patients)
  2. HbSC

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3. HbS/ $\beta^+$  thalassemia
4. HbS/ $\beta^0$  thalassemia
5. SS alpha thal (includes some unmapped patients)
6. S/ $\beta^0$  + alpha thalassemia
7. S delta  $\beta^0$  thalassemia
8. Other.

In addition, there is a small group of patients with a **HEMO** value of “9” (transfused). Many of the patients in this **HEMO** category were transfused at entry and continued to be transfused during the entire study period. There are also some patients who have no CDC hemoglobin electrophoresis results and consequently have a missing value for this variable.

- **HEMO2** – is the variable name for the hemoglobin diagnosis based on local (not CDC) results. For the infant cohort only, if there is no CDC result (see **HEMO** above) or the center had additional information, which was inconsistent with the CDC diagnosis, the results from the local lab are recorded. The value of **HEMO2** can be used to “update” the **HEMO** value to reduce the number of patients excluded from analyses because of missing **HEMO** information.
- **IDCHANGE** – is the variable name for whether or not a patient changed ID #s and/or centers during the study.
- **IN\_SIR** – is the variable name for whether or not the patient case was initialized on the SIR database during Phase 1. There are three infant cohort patients with a value of “0” for this variable. This indicates that the Phase 1 entry data for these patients was received AFTER the Phase 1 database was “closed”. Although they do have some roster information in the SAS **R09.SD2** dataset, no data for them exist in any of the other Phase 1 datasets.
- **LINENO** – is a 2-digit integer that denotes the line number on Form 1, which contains sex, birthdate information for the patient.
- **MOE** – is the variable name for month of entry. March 1979 was defined as the starting month. The value of **MOE** for any patient entered during or prior to March 1979 is “1”. The value of **MOE** is missing for patients entered after May 1987 since May 1987 is study month #99 and **MOE** was defined with a field length of only 2 digits.

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- **PHASE2** – is the variable name for whether or not an infant cohort patient participated in the infant cohort (pediatric) component of CSSCD Phase 2 study, which began in September 1989. Documentation for data collected during the CSSCD Phase 2 study is included in a separate manual.
- **PHASE2A** – is the variable name for whether or not an adult cohort patient (born before 1/1/56) participated in the adult component of the CSSCD Phase 2 study, which began in September 1989. Documentation for data collected during the CSSCD Phase 2 study is included in a separate manual.
- **PHASE3** – is the variable name for whether or not an infant cohort patient participated in the CSSCD Phase 3 study, which began in April 1994. Documentation for data collected during the CSSCD Phase 3 study is included in a separate manual.
- **PTYPE** – is the variable name for patient type (full-protocol (A-status) vs. semi-protocol (B-status)). Full protocol patients were followed for both routine visits and clinical events. Semi-protocol patients were those followed for routine visits only. Patients with **PTYPE=2** (semi-protocol) should not be included in any clinical event incidence analysis. The source of information for this variable was the Patient Demographic form (Form 2). The majority of the 185 semi-protocol patients were followed at 3 clinical centers (A, BB and Y) which recruited many patients from rural areas.
- **RACE** – is the variable name for race of patient. The source of information for this variable was Form #2 (Patient Demographic Form).
- **REFERRED** – is the variable name for whether a newborn\* was identified by newborn screening or referred for entry. The value for this variable was initialized to “0” (not applicable) when the case record was loaded to the database. Updating of this variable to “referred” vs. “identified” based on information for the clinic was discontinued after study month 36. Therefore, the majority of newborns have a value of “3” (not determined).

Most patients with a value of “3” were probably identified. A value of “1” (cord blood) for the variable **F14SRCHB** in **R14.SD2** or a **F14HBDT** date within 5 days of an infant’s birth would indicate the baby was identified by newborn screening.

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\* Note: Newborns were originally defined as those entered at < 5 months of age; in November 1986, the definition was changed to include all patients entered at < 6 months of age.

- **ROSTER** – is the variable name for status of patient prior to entry. Patients with **ROSTER** value of “1” (“yes”) are those who had been followed or seen at least once during the 2-year period preceding the start of the study in March 1979. They were included on a coded listing submitted to the Statistical Coordinating Center in late 1978. Patients listed on these clinical rosters were then randomized by the SCC in order to determine the entry order of patients within each clinic (See Gaston et al, 1987)
- **SEX** – is the variable name for sex of the patient. The source of information for this variable was Form #1 (Household Enumeration Form) or, less frequently, Form #2 (Patient Demographic Form).
- **STATUS** – is the variable name for study status of the patient at the end of follow-up during Phase 1. Patients with a value of “1” (active) were active through the end of follow-up for clinical events (05/31/86 for patients entered at  $\geq 6$  months of age; 09/30/88 for patients entered at < 6 months of age). Patients with a value of “3” (lost to follow-up) became inactive during the study (not seen for more than 2 years). The variable **STATUSD** (end of follow-up date) for these patients was computed to be **LASTSEEN** + 90 days (See **STATUSD** for reasons a patient with **STATUS**=3 may have a **LASTSEEN** date which is greater than **STATUSD**). Patients with a value of “5” (dead) died prior to the end of the study (09/30/88). The value of **STATUSD** for these patients is the date of death.  
\*\*\* Also see variables **STATUSD** and **LASTSEEN** \*\*\*
- **VARDATE** – is the variable name for date aseptic necrosis was diagnosed. In November 1984, a memo requesting date of diagnosis of aseptic necrosis in patients diagnosed prior to this date was sent to the clinical centers. Supposedly the value for this variable is based on the response from the appropriate clinical center.  
\*\*\* Also see variables **ANSTAT** & **ANDATE**, Section 8.2, and Sections 6.3 & 6.4

### N. Computed Variables:

1. Age Variables (**ENTRYAGE**, **CURRAGEY**, **CURRAGEM**, **EPROTO**, **CPROTO**)

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- **ENTRYAGE** – is a 2 digit integer which was computed on the database:  
**ENTRYAGE**=integer ((**DOE-BIRTHDAY**)/365)
  - **EPROTO** – is the variable name for the entry protocol of the patient. The value was computed on the SIR database. There are 6 valid values:
    - any patient who was entered at  $\leq 152$  days of age and has an **EPROTO** value of 2 is a “newborn with control”
    - any patient who was entered at  $\leq 152$  days of age and has an **EPROTO** value of 3 is a “newborn without control”
    - any patient entered between 152 and 730 days of age (Pediatric < 2) has an **EPROTO** value of 4
    - any patient entered between 2 and 10 years of age (Pediatric  $\geq 2$ ) has an **EPROTO** value of 5
    - any patient entered between 10 and 20 years of age (Adolescent) has an **EPROTO** value of 6
    - any patient entered at  $\geq 20$  years of age (Adult) has an **EPROTO** value of 7
  - **CURRAGEY** – is the variable name for current age in years which was recomputed on the database every month regardless of the life status of the patient: **CURRAGEY**=integer ((**TODAY-BIRTHDAY**)/365)
  - **CURRAGEM** – is the variable name for current age in months which was recomputed on the database every month regardless of the life status of the patient: **CURRAGEM**=integer ((**TODAY-BIRTHDAY**)/30.4)
  - **CPROTO** – is the variable name for current protocol status which was recomputed on the database each month using the current age of the patient (See **EPROTO**)
2. Routine Follow-up Visit Status Variables (**INFLOAD**, **INF2**, **INT1**, **ANN1**, **AN2**, **INT3**, **ANN3**, **ANN4**, **ANN5**, **ANN6**, **ANN7**, **ANN8**, **ANN9**)

For patients entered at < 2 years of age, dates for scheduling biannual and annual visits were based on time from birthdate (**BIRTHDAY**). For patients entered at  $\geq 2$  years of age, dates for scheduling biannual and annual visits were based on time from entry date (**DOE**). At the time a “Record” 9 was loaded to the database, all follow-up visit status variables were initialized to “0” (not required). Each month, values for routine visit status variables were recomputed on the

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database. As an annual (or interim) visit became due, the appropriate visit status variable was changed for “0” to “9” (due, missing). The value was adjusted to “5” (dead) for patients who died prior to the time for scheduling. Records in **R1722.SD2** and **R25.SD2** were then checked and the appropriate visit status set to “1” (loaded) if a record with a cycle # (**F17CYCLE** or **F25CYCLE**) corresponding to the needed visit was found. Based on responses received from clinics on the monthly calendars regarding the status of a scheduled visit, the value for the visit was updated to 3, 4, 5, 6, 7, or 8 if the record for the visit was due and not on the database.

For patients entered at  $\geq 6$  months of age, a final (exit) visit was due between 06/01/86 and 06/01/87. Once a routine visit record (**R25.SD2**) or a Life Status record (**R92.SD2**) done after 05/31/86 was on the database, subsequent annual visits were set to “0” (not required).

The visit status variables **INFLOAD** and **INF2** are applicable only for patients entered at  $< 2$  years of age. The value of **INFLOAD** is the cycle # (infant’s age in months) at the time of the last Infant Interim clinic visit. This value was computed by searching through records in **R16.SD2** and **R24.SD2** and making **INFLOAD** equal to the highest cycle # found. **INF2** is the variable name for whether a patient entered at  $< 2$  graduated to the pediatric protocol at age 2. If a patient in this entry age group has a routine visit (i.e., a record exists in **R1121.SD2**, **R1722.SD2** or **R25.SD2**) which was done after age 2, the value of **INF2** is “1” (loaded, graduated).

### 3. Special Studies Status Variables (**SHOULDER**, **HIP**, **PFLMSTAT**, **SONOGRAM**, **SPLNSTAT**, **PFTSTAT**, **CARDSTAT**, **OCEXSTAT**, **PSYSTAT**, **PENSTUDY**)

The variables listed above were used to facilitate monitoring of special studies. The table below lists the section of the manual which describes in detail which patients needed these studies and the time periods during which data were collected:

Special Study Status Variable	Special Study	SAS Dataset	See Section
<b>SHOULDER</b>	Shoulder x-ray	<b>R75.SD2</b>	6.3
<b>HIP</b>	Hip x-ray	<b>R76.SD2</b>	6.4
<b>PFLMSTAT</b>	Plain film of abdomen	<b>R77.SD2</b>	6.6.1
<b>SONOGRAM</b>	Sonogram, Oral cholecystogram	<b>R78.SD2</b> <b>R79.SD2</b>	6.6.2 6.6.3

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<b>SPLNSTAT</b>	Spleen scan	<b>R26.SD2</b>	6.5
<b>PFTSTAT</b>	Pulmonary function test	<b>R94.SD2</b>	6.8
<b>CARDSTAT</b>	Cardiac evaluation	<b>R97.SD2</b>	6.9
		<b>R98.SD2</b>	
		<b>R99.SD2</b>	
<b>OCEXSTAT</b>	Ocular exam	<b>R18.SD2</b>	6.7
		<b>R19.SD2</b>	
<b>PSYSTAT</b>	Psychosocial study	<b>R67.SD2</b>	6.10
		<b>R68.SD2</b>	
		<b>R69.SD2</b>	
		<b>R73.SD2</b>	
		<b>R74.SD2</b>	
<b>PENSTUDY</b>	Comfort measures for pain	<b>R56.SD2</b>	6.12

#### 4. Special Events Status Variables (**SEIZSTAT**, **MENSTAT**, **CVASTAT**, **ANSTAT**, **ANDATE**)

The variables listed above were used to monitor neurologic events and aseptic necrosis. Values for these variables were initialized to “0” (no event or not applicable) at the time the case record was loaded to the database.

- Neurologic Event Variables

Subsequently, the past medical history records (10, 14, 15) were searched and the value of the appropriate neurologic status variable (**SEIZSTAT**, **MENSTAT**, **CVASTAT**) set to “3” if the neurologic event occurred prior to entry. Next, the appropriate on-study neurologic event records and death record were searched monthly to determine whether the event occurred while on study. If the event occurred while on study, values of 0 were reset to “1” (1<sup>st</sup> event on study) and values of “3” were reset to “2” (before & in study). [See Neurologic Events Section 7.5, Section 7.9, and Section 9.5]

- Aseptic Necrosis Variables

After the **ANSTAT** variable was initialized to “0”, the Aseptic Necrosis record (“Record” 64) was processed monthly in order to determine whether a form for this chronic event was completed. If a “Record” 64 was found, **ANSTAT** was set to “2” (current problem) and **ANDATE** was computed to be the date of the first form 64 on the database (earliest **F64DATE**). Scheduling of biannual or annual aseptic necrosis follow-up visits were originally based on this date. Later in the study, however, scheduling of AN follow-up visits was changed to coincide with the date of a routine follow-up visit [See “Record” 9 variable **VARDATE**, Section 8.2, and Sections 6.3 & 6.4].

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### 5. Overall Study Status Variables (**LASTSEEN**, **STATUSD**)

An understanding of these two variables plus the variable **STATUS** is important for anyone interested in patient follow-up time, attrition rates, death rates, or analysis of incidence of any clinical event.

- **LASTSEEN** – when the **CASE** record (“Record” 9) for a patient was added to the SIR database, the variable **LASTSEEN** was computed to be the date of entry (**DOE**). In the schema definition for most record types which had a “date patient seen” variable, a compute command for **LASTSEEN** was included. During Batch Data Input, as each input record was read, the following computation which updated **LASTSEEN** was performed:

If **FxxDATE** (date patient seen) > **LASTSEEN** then **LASTSEEN=FxxDATE**

NOTE: For patients who died, the value of **LASTSEEN** is not necessarily the date of death [See **STATUSD**]

- **STATUSD** – is the end of follow-up date. The value of **STATUS** is either “1” (active), “3” (lost to follow-up), or “5” (dead).
- If the status of a patient is “1” (active) and the patient was entered at > 6 months of age, **STATUSD**=05/31/86, the date follow-up of clinical events was discontinued.

\*\*\* For incidence analysis of most clinical events *except death* which continued to be monitored through 09/30/88 for all patients, the end of follow-up for “active” patients (**STATUS**=1) is 05/31/86. However, there are a few events (e.g., acute chest) which stopped being monitored for some subgroups of patients before 05/31/86. Therefore, it is important to review the section dealing with the event of interest to make sure the end of follow-up is computed correctly for a given event.

- If the status of a patient is “1” (active) and the patients was entered at < 6 months of age, **STATUSD**=09/30/88, the date follow-up of clinical events for this entry age group was discontinued.
- If the status of a patient is “5” (dead), **STATUSD** is the date of death.

**LASTSEEN** may be much earlier than the date of death if the patient was “inactive” for more than 2 years and died outside of a CSSCD study center. Depending on the analysis being done, end of follow-up for patients who have died may be equal to **STATUSD** (date of death), **LASTSEEN+90**, the date

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reporting of all clinical events was discontinued for patients entered at  $\geq 6$  months (05/31/86), or the date reporting of a specific clinical event was discontinued.

- If the status of a patient is “3” (lost to follow-up), the end of follow-up (**STATUSD**) in general = **LASTSEEN** + 90 days. During the course of the study, a patient was considered to be “inactive” or “LTFU” if he/she had not been seen for more than two years (**LASTSEEN** < **TODAY**-730). Once a patient’s status was changed to “inactive”, it was never changed back to “active” even if the patient became active at a later date. As a result, there are patients on the database who have a **STATUS** of “3” (LTFU) with a **LASTSEEN** date which is > **STATUSD**. However, for purposes of event incidence analyses, follow-up time and events occurring after **STATUSD** for patients with **STATUS**=3 are excluded from the appropriate numerators or denominators. It is possible that patients with a **STATUS** of “5” (dead) at one time had a status of “3” (LTFU) on the database. Therefore, it is important in incidence analyses to determine whether the end of follow-up for patients who have died should be **LASTSEEN**+90 or **STATUSD** (date of death), or some other date.
6. Other Computed Variables (**RELATION**, **ISFAMID**, **G6PDEF**, **PNEUVAX**, **PNEUDTE**)
- **RELATION** – is the variable name for the relationship of the patient to the head of the household. The value for this variable was computed on the SIR database by processing “Record” 1 and making **RELATION**=**F01RLx** where x equals the **LINENO** of the patient.
  - **ISFAMID** – is the variable name that indicates whether the patient is the family ID patient. If **ANONID**=**FAMID2** (see Section H: **FAMID2** ), then **ISFAMID** was computed to be “1” (yes, Family ID). If **ANONID** NE **FAMID2**, then **ISFAMID** was computed to be “0” (no, not Family ID). In households with only 1 study participant, **ISFAMID**=1. In households with more than one participating study patient, only one of the participants has a **FAMID2** value of “1”. Only 1 set of some entry demographic forms (1, 3, 4) was required per household. The **ANONID** for the records used for storing the data from these forms for all household members participating (“Records” 1, 3) will be the

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**ISFAMID**=1 patient. In order to link the records of **ISFAMID**=0 patients to the appropriate demographic records, **FAMID2** rather than **ANONID** has to be used as the linking variable [also See Section 3].

- **G6PDEF** – is the variable name for G-6-PD deficiency. Only HbSS patients entered at  $\geq 2$  years of age who have G-6-PD results [See Section 5.1] have a value for this variable. A modified K-means cluster analysis was used to classify patients into a G-6-PD genotype of either deficient or non-deficient using hexokinase and G-6-PD activities as the classification variables [See Steinberg et al, 1988].
- **PNEUVAX** – is the variable name for whether the patient received pneumovax. Only patients who received pneumovax (confirmed and missing confirmation responses) have a value for this variable. Past medical history “records” (10, 15) and routine visit “records” (17, 25, 24) were processed in order to determine whether and when the patient received pneumovax. The 4 digit date variable **PNEUDTE** which has an MMY date format, was computed to be the earliest date of immunization reported. Because the date of immunization was collected on the past medical history form (Form 10) but not stored in the SAS dataset (**R10.SD2**), the date of immunization was computed to be the month and year of entry for patients immunized prior to entry according to Form 10.

### O. Inter-Relationship With Other Datasets:

Most of the variables in this dataset relate to variables in other datasets since the values for many of these variables were derived by using data stored in other datasets. The summary table below lists, for many of these variables, sections in the documentation manual and datasets which should be referenced for these variables.

Variable	Section in Documentation Manual	SAS Dataset
<b>Routine Follow-up Visit Status</b>		
<b>INFLOAD</b>	4	<b>R16.SD2</b> <b>R24.SD2</b>
<b>INF2</b>	4	<b>R1121.SD2</b> <b>R1722.SD2</b> <b>R25.SD2</b>
<b>INT1 *</b>	4	<b>R1722.SD2</b> ( <b>F17CYCLE=26</b> )

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<b>ANN1 *</b>	4	<b>R1722.SD2</b>	<b>(F17CYCLE=27)</b>
		<b>R25.SD2</b>	<b>(F25CYCLE=27)</b>
<b>ANN2 *</b>	4	<b>R1722.SD2</b>	<b>(F17CYCLE=29)</b>
		<b>R25.SD2</b>	<b>(F25CYCLE=29)</b>
<b>INT3 *</b>	4	<b>R1722.SD2</b>	<b>(F17CYCLE=30)</b>
<b>ANN3 *</b>	4	<b>R1722.SD2</b>	<b>(F17CYCLE=31)</b>
		<b>R25.SD2</b>	<b>(F25CYCLE=31)</b>
<b>ANN4 *</b>	4	<b>R1722.SD2</b>	<b>(F17CYCLE=33)</b>
		<b>R25.SD2</b>	<b>(F25CYCLE=33)</b>

Variable                      Section in  
Documentation Manual      SAS Dataset

**Routine Follow-up Visit Status (continued)**

<b>ANN5 *</b>	4	<b>R25.SD2</b>	<b>(F25CYCLE=35)</b>
<b>ANN6 *</b>	4	<b>R25.SD2</b>	<b>(F25CYCLE=37)</b>
<b>ANN7 *</b>	4	<b>R25.SD2</b>	<b>(F25CYCLE=39)</b>
<b>ANN8 *</b>	4	<b>R25.SD2</b>	<b>(F25CYCLE=41)</b>
<b>ANN9 *</b>	4	<b>R25.SD2</b>	<b>(F25CYCLE=43)</b>

\* If value is “1” (loaded), patient should have a record with cycle # value listed in the SAS dataset column.

**Special Lab**

<b>HEMO</b>	5	<b>R06.SD2</b>	
		<b>R04.SD2</b>	
<b>G6PDEF</b>	5	<b>R06.SD2</b>	

**Special Studies Status**

<b>SHOULDER,</b>	6.3	<b>R75.SD2</b>	
<b>VARDATE</b>	8.2	<b>R64.SD2</b>	
		<b>R65.SD2</b>	
	2	<b>R10.SD2</b>	<b>(F10ASNE)</b>
	9.1	<b>R83.SD2</b>	
		<b>(F83ICDA=</b>	
		81.81 or	
		81.83, e.g.)	
<b>HIP, VARDATE</b>	6.4	<b>R76.SD2</b>	
	8.2	<b>R64.SD2</b>	
		<b>R65.SD2</b>	
	2	<b>R10.SD2</b>	<b>(F10ASNE, F10OPHRD, F10OPHR)</b>
	4	<b>25 (F25SURHP, F25DTEHP)</b>	
	9.1	<b>83 (F83ICDA=81.5 or 81.6, e.g.)</b>	
<b>PFLMSTAT,</b>	6.6	<b>R77.SD2</b>	
<b>SONOGRAM</b>		<b>R78.SD2</b>	
		<b>R79.SD2</b>	
	7.3	<b>R34.SD2</b>	
	7.9	<b>R53.SD2</b>	
		<b>(RUQ section)</b>	

**1.0: Patient Roster (Case) Information – “Record” 9**

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	2	<b>R10.SD2</b> (F10OPGBD, F10OPPGB, F10ACHO)
	4	<b>R25.SD2</b> (F25GALB1-2, F25GALD1-2)
	9.1	<b>F83.SD2</b> (F83ICDA=51.20- 51.22)

Variable	Section in Documentation Manual	SAS Dataset
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**Special Studies Status (continued)**

<b>SPLNSTAT</b>	6.5	<b>R26.SD2</b>
<b>PFTSTAT</b>	6.8	<b>R94.SD2</b>
<b>CARDSTAT</b>	6.9	<b>R97.SD2</b> <b>R98.SD2</b> <b>R99.SD2</b>
<b>OCEXSTAT</b>	6.7	<b>R18.SD2</b> <b>R19.SD2</b>
<b>PSYSTAT</b>	6.10	<b>R67.SD2</b> <b>R68.SD2</b> <b>R69.SD2</b> <b>R73.SD2</b> <b>R74.SD2</b>
<b>PENSTUDY</b>	6.12	<b>R56.SD2</b>

Variable	Section in Documentation Manual	SAS Dataset
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**Special Events**

<b>SEIZSTAT</b>	2	<b>R10.SD2 (F10SEIZ)</b> <b>R15.SD2 (F15SEIZ)</b>
	7.5	<b>R40.SD2</b>
	7.9	<b>R53.SD2</b> (seizure section)
	4	<b>R17.SD2</b> <b>R25.SD2</b> (seizure, seizure med variables)

**1.0: Patient Roster (Case) Information – “Record” 9**

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<b>MENSTAT</b>	2	R10.SD2 (F10MENI) R15.SD2 (F15MENI, F15HMENI) R14.SD2 (F14MENI)
	7.5	R42.SD2
	7.9	R53.SD2 (infection section)
	9.5	R91.SD2 (F91CAUSE=1, F91MENOR, F91MENSUR)
<b>CVASTAT</b>	2	R10.SD2 (F10STRK) R15.SD2 (F15STRK)
	7.5	R44.SD2, R42.SD2
	7.9	R53.SD2 (CVA section)
	9.5	R91.SD2 (F91IMCSE=4)

Variable	Section in Documentation Manual	SAS Dataset
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**Special Events (continued)**

<b>ANSTAT, ANDATE, VARDATE</b>	8.2	R64.SD2, R65.SD2
	6.3, 6.4	R75.SD2, R76.SD2
	2	R10.SD2 (F10ASNE, F10OPHRD, F10OPHR)
	4	R25.SD2 (F25SURHP, F25DTEHP)
	9.1	R83.SD2 (F83ICDA=81.81, 81.83, 81.5, 81.6)

**Other**

<b>RELATION</b>	3	R01.SD2 (F01RL1-9)
<b>PNEUVAX, PNEUDTE</b>	2	R10.SD2 (F10IMPNE) R15.SD2 (F15PNE, F15PNEDT)
	4	R24.SD2 (F24PNE, F24PNEDT, F24PNEMR) R17.SD2 (F17PNE, F17PNEDT, F17PNEMR) R25.SD2 (F25PNE, F25PNEDT, F25PNEMR)
	7.5	R42.SD2 (F42IMPNE, F42PNDTE, F42PREC)
	7.7	R48.SD2 (F48PNE, F48PNEDT, F48PNEMR)
	7.9	R53.SD2 (F53PNEU, F53PNED1-3)

**1.0: Patient Roster (Case) Information – “Record” 9**

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**ELIGIBLE**

**2**

**R14.SD2 (F14GSAGE,  
FTYPDL, F14APGR5,  
F14WGT)**

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

The SAS System

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The CONTENTS Procedure

Data Set Name	OUT1.R09	Observations	4085
Member Type	DATA	Variables	61
Engine	V9	Indexes	0
Created	14:07 Monday, August 28, 2006	Observation Length	488
Last Modified	14:07 Monday, August 28, 2006	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	125
First Data Page	1
Max Obs per Page	33
Obs in First Data Page	16
Number of Data Set Repairs	0
File Name	r09.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
7	ANN1	Num	8	FIRST ANNUAL CLINIC VISIT
8	ANN2	Num	8	SECOND ANNUAL CLINIC VISIT
9	ANN3	Num	8	THIRD ANNUAL CLINIC VISIT
10	ANN4	Num	8	FOURTH ANNUAL CLINIC VISIT
11	ANN5	Num	8	FIFTH ANNUAL CLINIC VISIT
12	ANN6	Num	8	SIXTH ANNUAL CLINIC VISIT
13	ANN7	Num	8	SEVENTH ANNUAL CLINIC VISIT
14	ANN8	Num	8	EIGHTH ANNUAL CLINIC VISIT
15	ANN9	Num	8	NINTH ANNUAL CLINIC VISIT
54	ANONID	Char	8	ANONYMIZED ID #
16	ANSTAT	Num	8	ASEPTIC NECROSIS
17	CARDSTAT	Num	8	CARDIOLOGY EVALUATION STATUS
18	CPROTO	Num	8	CURRENT PROTOCOL
19	CURRAGEM	Num	8	CURRENT AGE (MONTHS)
20	CURRAGEY	Num	8	CURRENT AGE (YEARS)
21	CVASTAT	Num	8	CEREBROVASCULAR ACCIDENT
50	DXSOURCE	Num	8	SOURCE OF HEMOGLOBIN DIAGNOSIS
22	ELIGIBLE	Num	8	NEWBORN ELIGIBLE FOR CONTROL
23	ENTRYAGE	Num	8	AGE AT ENTRY (YRS)
24	EPROTO	Num	8	ENTRY PROTOCOL

SECTION 1.0 PATIENT ROSTER (CASE) INFORMATION

"RECORD" 9

**CODEBOOK FOR CSSCD 'RECORD' 9**

**PHASE 1 PATIENT ROSTER**

CSSCD FULL COHORT PATIENTS

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56	FAMID2	Char	8	ANONYMIZED FAMILY ID #
25	G6PDEF	Num	8	G-6-PD DEFICIENCY
53	HASTUBE	Num	8	DNA SAMPLE AT REPOSITORY?
2	HEMO	Num	8	CDC HEMOGLOBIN DIAGNOSIS
51	HEMO2	Num	8	LOCAL HEMOGLOBIN DIAGNOSIS
26	HIP	Num	8	HIP X-RAY STATUS
52	IDCHANGE	Num	8	CHANGED ID AND/OR CLINIC

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SECTION 1.0 PATIENT ROSTER (CASE) INFORMATION

"RECORD" 9

**CODEBOOK FOR CSSCD 'RECORD' 9**  
**PHASE 1 PATIENT ROSTER**  
 CSSCD FULL COHORT PATIENTS

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The SAS System

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The CONTENTS Procedure

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
28	INF2	Num	8	INTAKE AT AGE 2 FORM FOR INFANTS
27	INFLOAD	Num	8	CYCLE # OF LATEST 16 OR 16E LOADED
29	INT1	Num	8	FIRST INTERIM CLINIC VISIT
30	INT3	Num	8	THIRD INTERIM CLINIC VISIT
49	IN_SIR	Num	8	HAD CASE INITIALIZED IN SIR?
31	ISFAMID	Num	8	FAMILY ID PATIENT
60	JANDATE	Num	8	1ST ASEPTIC NECROSIS FORM - DY SINCE DOE
57	JLASTSEN	Num	8	LAST SEEN PHASE 1 - DAYS SINCE DOE
58	JPNEUDTE	Num	8	DATE OF PNEUMOVAX - DAYS SINCE DOE
59	JSTATUSD	Num	8	PHASE 1 PATIENT STAT - DAYS SINCE DOE
61	JVARDATE	Num	8	ASEPTIC NECROSIS DIAG - DAYS SINCE DOE
32	LINENO	Num	8	LINE NUMBER
33	MENSTAT	Num	8	MENINGITIS
34	MOE	Num	8	MONTH OF ENTRY
35	OCEXSTAT	Num	8	OCULAR EXAM STATUS
36	PENSTUDY	Num	8	PAIN COMFORT MEASURES STUDY
37	PFLMSTAT	Num	8	PLAIN FILM OF ABDOMEN
38	PFTSTAT	Num	8	PULMONARY FUNCTION TEST
5	PHASE2	Num	8	INFANT ENROLLED IN CSSCD PHASE 2
6	PHASE3	Num	8	INFANT ENROLLED IN CSSCD PHASE 3
55	PHASE2A	Num	8	ADULT ENROLLED IN CSSCD PHASE 2
39	PNEUVAX	Num	8	HAS PATIENT RECEIVED PNEUMOVAX
40	PSYSTAT	Num	8	PSYCHOSOCIAL STUDY STATUS
3	PTYPE	Num	8	PROTOCOL TYPE DURING PHASE 1
41	RACE	Num	8	RACE
42	REFERRED	Num	8	NEWBORN IDENTIFIED OR REFERRED
48	RELATION	Num	8	RELATION TO HEAD OF HOUSEHOLD
43	ROSTER	Num	8	ROSTER PATIENT
44	SEIZSTAT	Num	8	SEIZURES
1	SEX	Num	8	GENDER
45	SHOULDER	Num	8	SHOULDER X-RAY STATUS
46	SONOGRAM	Num	8	SONOGRAM NEEDED
47	SPLNSTAT	Num	8	SPLEEN SCAN
4	STATUS	Num	8	STATUS AT END OF PHASE 1

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

\*\*\*\*\*  
\* R09.FMT contains value labels for numerical codes assigned to categorical\*  
\* variables in the SAS dataset R09.SD2 \*  
\*\*\*\*\*;

PROC FORMAT;

\* FORMAT ANNSTAT IS DEFINED FOR VARIABLES ANN1 ANN2 ANN3 ANN4 ANN5  
ANN6 ANN7 ANN8 ANN9 INT1 INT3;

VALUE ANNSTAT  
0 = 'NOT REQUIRED'  
1 = 'LOADED'  
2 = 'NOT DONE'  
3 = 'REPORTED DONE'  
4 = 'SICK'  
5 = 'DIED'  
6 = 'REFUSED'  
7 = 'MOVED'  
8 = 'LOST TO F.U.'  
9 = 'MISSING';

\* FORMAT ANSTAT IS DEFINED FOR VARIABLE ANSTAT;

VALUE ANSTAT  
0 = 'NO PROBLEMS'  
1 = 'RESOLVED PROBLEMS'  
2 = 'CURRENT PROBLEM';

\* FORMAT CARDSTAT IS DEFINED FOR VARIABLE CARDSTAT;

VALUE CARDSTAT  
0 = 'NOT REQUIRED'  
1 = '#1 NOT DONE'  
2 = 'REFUSED #1'  
3 = 'INACT. FOR #1'  
4 = 'NO #1, MED. REASON'  
5 = '? DONE, NO FORM RECD'  
6 = 'NEED STUDY #2'  
11 = 'NO #2, TRNSFRD'  
12 = 'REFUSED #2'  
13 = 'INACT. FOR #2'  
14 = 'NO #2, MED. REASON'  
15 = '#2 REPORTED DONE'  
16 = '#2 DONE';

\* FORMAT CPROTO IS DEFINED FOR VARIABLE CPROTO;

VALUE CPROTO  
1 = 'CONTROL'  
2 = 'NEWBORN W CNTRL'  
3 = 'NEWBORN WO CNTRL'  
4 = 'PEDIATRIC < 2'  
5 = 'PEDIATRIC >= 2'  
6 = 'ADOLESCENT'  
7 = 'ADULT';

\* FORMAT CVASTAT IS DEFINED FOR VARIABLE CVASTAT;

VALUE CVASTAT  
1 = '1ST CVA IN STUDY'  
2 = 'CVA BEFORE & IN STUDY'  
3 = 'CVA BEFORE STUDY';

**CODEBOOK FOR CSSCD 'RECORD' 9**  
**PHASE 1 PATIENT ROSTER**  
CSSCD FULL COHORT PATIENTS

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\* FORMAT ELIGIBLE IS DEFINED FOR VARIABLE ELIGIBLE;

VALUE ELIGIBLE  
0 = 'N.A.'  
1 = 'NOT ELIGIBLE'  
2 = 'ELIGIBLE'  
3 = 'NOT DETERMINED';

\* FORMAT EPROTO IS DEFINED FOR VARIABLE EPROTO;

VALUE EPROTO  
1 = 'CONTROL'  
2 = 'NEWBORN W CNTRL'  
3 = 'NEWBORN WO CNTRL'  
4 = 'PEDIATRIC < 2'  
5 = 'PEDIATRIC >= 2'  
6 = 'ADOLESCENT'  
7 = 'ADULT';

\* FORMAT G6PDEF IS DEFINED FOR VARIABLE G6PDEF;

VALUE G6PDEF  
1 = 'G-6-PD DEFICIENT'  
2 = 'NOT DEFICIENT';

\* FORMAT HEMO IS DEFINED FOR VARIABLE HEMO;

VALUE HEMO  
0 = 'CONTROL'  
1 = 'SS'  
2 = 'SC'  
3 = 'S B+ THAL'  
4 = 'S B0 THAL'  
5 = 'SS ALPHA'  
6 = 'SB0 + ALPHA THAL'  
7 = 'SB0 + DELTA THAL'  
8 = 'OTHER VARIANT'  
9 = 'TRANSFUSED';

\* FORMAT HIP IS DEFINED FOR VARIABLE HIP;

VALUE HIP  
0 = 'NOT REQUIRED'  
1 = '#1 NOT DONE'  
2 = '#2 NOT DUE'  
3 = 'INACTIVE FOR #2'  
4 = '#2 NOT DONE'  
5 = '#2 DONE'  
20 = 'CONTROL-NEED REP'  
22 = 'CONTROL-REP DONE'  
25 = 'CONTROL-INACTIVE'  
26 = 'CONTROL-AN LATER';

\* FORMAT INF2F IS DEFINED FOR VARIABLE INF2;

VALUE INF2F  
0 = 'NOT REQUIRED'  
1 = 'LOADED'  
2 = 'NOT DONE'  
3 = 'REPORTED DONE'

**CODEBOOK FOR CSSCD 'RECORD' 9**  
**PHASE 1 PATIENT ROSTER**  
CSSCD FULL COHORT PATIENTS

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4 = 'SICK'  
5 = 'DIED'  
6 = 'REFUSED'  
7 = 'MOVED'  
8 = 'LOST TO F.U.'  
9 = 'MISSING';

\* FORMAT ISFAMID IS DEFINED FOR VARIABLE ISFAMID;

VALUE ISFAMID  
0 = 'NOT THE FAMILY ID'  
1 = 'FAMILY ID';

\* FORMAT MENSTAT IS DEFINED FOR VARIABLE MENSTAT;

VALUE MENSTAT  
1 = '1ST MENINGITIS IN STUDY'  
2 = 'MENINGITIS BEFORE & IN STUDY'  
3 = 'MENINGITIS BEFORE STUDY';

\* FORMAT MOE IS DEFINED FOR VARIABLE MOE;

VALUE MOE  
1 = '<JAN 84'  
2 = '>=JAN 84';

\* FORMAT OCEXSTAT IS DEFINED FOR VARIABLE OCEXSTAT;

VALUE OCEXSTAT  
0 = 'NEVER CHOSEN'  
1 = 'TO BE EXAMINED'  
2 = 'CHOSEN BUT DELETED'  
3 = 'EXAM COMPLETE';

\* FORMAT PENSTUDY IS DEFINED FOR VARIABLE PENSTUDY;

VALUE PENSTUDY  
0 = 'NOT REQUIRED'  
1 = 'NEED QUESTIONNAIRE'  
2 = 'QUESTIONNAIRE DONE'  
3 = 'DONE,NOT REQUIRED'  
5 = 'NOT DONE,DIED'  
6 = 'NOT DONE,REFUSED'  
7 = 'NOT DONE,MOVED'  
8 = 'NOT DONE,LTFU'  
9 = 'NOT DONE,NO REAS.';

\* FORMAT PFLMSTAT IS DEFINED FOR VARIABLE PFLMSTAT;

VALUE PFLMSTAT  
0 = 'NOT NEEDED'  
1 = 'NEED TEST'  
2 = 'REFUSED'  
3 = 'NOT DONE-INACTIVE'  
4 = 'CHOLECYSTECTOMY'  
5 = 'NOT DONE MED. REASON'  
6 = 'DONE'  
7 = 'XRAY DONE, XGAL MISS.';

\* FORMAT PFTSTAT IS DEFINED FOR VARIABLE PFTSTAT;

**CODEBOOK FOR CSSCD 'RECORD' 9**  
**PHASE 1 PATIENT ROSTER**  
CSSCD FULL COHORT PATIENTS

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VALUE PFTSTAT  
0 = 'NOT NEEDED'  
1 = 'TEST NEEDED'  
2 = 'REFUSED TEST'  
3 = 'NOT DONE-INACTIVE'  
4 = 'NOT DONE MED. REASON'  
5 = '? DONE, NO FORM RECD'  
6 = 'DONE'  
15 = 'REPORTED DONE-CARD.'  
16 = 'DONE-CARDIAC STUDY';

\* FORMAT PNEUVAX IS DEFINED FOR VARIABLE PNEUVAX;

VALUE PNEUVAX  
1 = 'RECEIVED,CONFIRMED'  
2 = 'REC'D,NO CONF. RESP.';

\* FORMAT PSYSTAT IS DEFINED FOR VARIABLE PSYSTAT;

VALUE PSYSTAT  
0 = 'NOT NEEDED'  
1 = 'NOT DONE - GRP 1,3'  
2 = 'NOT DONE - GRP 2,4'  
3 = 'NOT DONE - GRP 5'  
4 = 'DONE - GRP 1,3'  
5 = 'DONE - GRP 2,4'  
6 = 'DONE - GRP 5';

\* FORMAT PTYPE IS DEFINED FOR VARIABLE PTYPE;

VALUE PTYPE  
1 = 'FULL PROTOCOL'  
2 = 'SEMI PROTOCOL';

\* FORMAT RACE IS DEFINED FOR VARIABLE RACE;

VALUE RACE  
1 = 'BLACK'  
3 = 'OTHER'

\* FORMAT REFERRED IS DEFINED FOR VARIABLE REFERRED;

VALUE REFERRED  
0 = 'N.A.'  
1 = 'IDENTIFIED'  
2 = 'REFERRED'  
3 = 'NOT DETERMINED';

\* FORMAT ROSTER IS DEFINED FOR VARIABLE ROSTER;

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

\* FORMAT SEIZSTAT IS DEFINED FOR VARIABLE SEIZSTAT;

VALUE SEIZSTAT  
1 = '1ST SEIZURE IN STUDY'

**CODEBOOK FOR CSSCD 'RECORD' 9**  
**PHASE 1 PATIENT ROSTER**  
CSSCD FULL COHORT PATIENTS

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2 = 'SEIZURES BEFORE & IN STUDY'  
3 = 'SEIZURES BEFORE STUDY';

\* FORMAT SEX IS DEFINED FOR VARIABLE SEX;

VALUE SEX  
1 = 'FEMALE'  
2 = 'MALE';

\* FORMAT SHOULDER IS DEFINED FOR VARIABLE SHOULDER;

VALUE SHOULDER  
0 = 'NOT REQUIRED'  
1 = '#1 NOT DONE'  
2 = '#2 NOT DUE'  
3 = 'INACTIVE FOR #2'  
4 = '#2 NOT DONE'  
5 = '#2 DONE'  
20 = 'CONTROL-NEED REP'  
22 = 'CONTROL-REP DONE'  
25 = 'CONTROL-INACTIVE'  
26 = 'CONTROL-AN LATER';

\* FORMAT SONOGRAM IS DEFINED FOR VARIABLE SONOGRAM;

VALUE SONOGRAM  
0 = 'N.A.'  
1 = 'NEED SONO #1'  
2 = 'SONO #1 DONE'  
3 = 'SONO NOT DONE, OC+ '  
4 = 'REPEAT PFLM + '  
5 = 'INACTIVE BEF EXT.'  
6 = 'SURG SINCE - PFLM'  
9 = 'UNKNOWN-NO GS RESP.'  
10 = 'N.A.-FIRST PFLM + '  
11 = 'NEED REPEAT'  
12 = 'REPEAT DONE'  
13 = 'OC + AFT - SONO'  
14 = 'PFLM + AFT - SONO'  
15 = 'INACTIVE AFT EXT'  
16 = 'SURG AFT - SONO'  
20 = 'NEED SONO-YNG PT'  
22 = 'SONO DONE-YNG PT'  
23 = 'ND-GS IN PAST-YNG'  
24 = 'CHOLECYST.-YNG PT'  
25 = 'ND-INACT.-YNG PT'  
26 = 'ND-REFUSED-YNG PT';

\* FORMAT SPLNSTAT IS DEFINED FOR VARIABLE SPLNSTAT;

VALUE SPLNSTAT  
0 = 'NOT NEEDED'  
1 = 'NOT NEEDED YET'  
2 = 'NEED SCAN NOW'  
3 = 'NEEDED BUT MISSED'  
4 = 'SCAN DONE TOO LATE'  
5 = 'SCAN COMPLETED'  
6 = 'SCAN NOT DONE'  
7 = 'DISCONTINUED';

\* FORMAT STATUS IS DEFINED FOR VARIABLE STATUS;

**CODEBOOK FOR CSSCD 'RECORD' 9**  
**PHASE 1 PATIENT ROSTER**  
CSSCD FULL COHORT PATIENTS

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VALUE STATUS

1 = 'ACTIVE'  
3 = 'LOST TO FOLLOW-UP'  
5 = 'DEAD';

\* FORMAT RELATION IS DEFINED FOR VARIABLE RELATION;

VALUE RELATION

1 = 'HEAD'  
2 = 'SPOUSE OF HEAD'  
3 = 'CHILD OF HEAD'  
4 = 'ADOPTED CHILD'  
5 = 'STEP CHILD'  
6 = 'OTH. BLOOD RELATIVE'  
7 = 'OTH. RELATIVE'  
8 = 'NON RELATIVE'  
9 = 'DK';

\* FORMAT NOYES IS DEFINED FOR VARIABLES HASTUBE IDCHANGE PHASE2  
PHASE3 PHASE2A;

VALUE NOYES

0 = 'NO'  
1 = 'YES';

\* FORMAT DXSOURCE IS DEFINED FOR VARIABLE DXSOURCE;

VALUE DXSOURCE

2 = 'FORM 14'  
3 = 'CLINIC EDIT';

\* FORMAT ANN1 ANN2 ANN3 ANN4 ANN5 ANN6 ANN7 ANN8 ANN9 INT1 INT3

ANNSTAT.  
ANSTAT ANSTAT.  
CARDSTAT CARDSTAT.  
CPROTO CPROTO.  
CVASTAT CVASTAT.  
ELIGIBLE ELIGIBLE.  
EPROTO EPROTO.  
G6PDEF G6PDEF.  
HEMO HEMO2 HEMO.  
HIP HIP.  
INF2 INF2F.  
ISFAMID ISFAMID.  
MENSTAT MENSTAT.  
MOE MOE.  
OCEXSTAT OCEXSTAT.  
PENSTUDY PENSTUDY.  
PFLMSTAT PFLMSTAT.  
PFTSTAT PFTSTAT.  
PNEUVAX PNEUVAX.  
PSYSTAT PSYSTAT.  
PTYPE PTYPE.  
RACE RACE.  
REFERRED REFERRED.  
ROSTER ROSTER.  
SEIZSTAT SEIZSTAT.  
SEX SEX.  
SHOULDER SHOULDER.  
SONOGRAM SONOGRAM.  
SPLNSTAT SPLNSTAT.  
STATUS STATUS.  
RELATION RELATION.  
HASTUBE IDCHANGE PHASE2 PHASE3 PHASE2A NOYES.

CODEBOOK FOR CSSCD 'RECORD' 9  
PHASE 1 PATIENT ROSTER  
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```
DXSOURCE DXSOURCE.  
;
```

```
RUN;  
QUIT;
```

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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HEMO ----- CDC HEMOGLOBIN DIAGNOSIS

type: numeric (float)  
label: HEMO,  
  
range: [-9,9] units: 1  
unique values: 10 coded missing: 38 / 4085

tabulation:

Freq.	Numeric	Label
4	-9	
2061	1	SS
883	2	SC
206	3	S B+ THAL
100	4	S B0 THAL
642	5	SS ALPHA
82	6	SBO + ALPHA THAL
10	7	SBO + DELTA THAL
2	8	OTHER VARIANT
57	9	TRANSFUSED

HEMO2 ----- LOCAL HEMOGLOBIN DIAGNOSIS

type: numeric (float)  
label: HEMO2  
  
range: [1,4] units: 1  
unique values: 4 coded missing: 4042 / 4085

tabulation:

Freq.	Numeric	Label
29	1	SS
9	2	SC
3	3	S B+ THAL
2	4	S B0 THAL

DXSOURCE ----- SOURCE OF HEMOGLOBIN DIAGNOSIS

type: numeric (float)  
label: DXSOURCE  
  
range: [2,3] units: 1  
unique values: 2 coded missing: 4042 / 4085

tabulation:

Freq.	Numeric	Label
22	2	FORM 14
21	3	CLINIC EDIT

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

SEX ----- GENDER

type: numeric (float)  
label: SEX  
  
range: [1,2] units: 1  
unique values: 2 coded missing: 0 / 4085

tabulation:	Freq.	Numeric	Label
	2088	1	FEMALE
	1997	2	MALE

RACE ----- RACE **MODIFIED**

type: numeric (float)  
label: RACE  
  
range: [-9,3] units: 1  
unique values: 4 coded missing: 13 / 4085

tabulation:	Freq.	Numeric	Label
	1	-9	
	3974	1	BLACK
	14	2	CAUCASIAN
	83	3	OTHER

CLINICL ----- CLINIC LETTER CODE

type: string (str2)  
  
unique values: 28 coded missing: 0 / 4085

tabulation:	Freq.	Value
	128	"A"
	69	"AA"
	84	"B"
	130	"BB"
	259	"C"
	117	"D"
	185	"E"
	175	"F"
	136	"G"
	113	"H"
	142	"I"
	173	"J"
	78	"K"
	23	"L"
	282	"M"
	132	"N"
	246	"O"
	68	"P"
	227	"Q"
	117	"R"
	155	"S"
	83	"T"

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

94 "U"  
146 "V"  
119 "W"  
125 "X"  
164 "Y"  
315 "Z"

MOE ----- MONTH OF ENTRY **MODIFIED**

type: numeric (float)  
label: MOE

range: [1,98] units: 1  
unique values: 97 coded missing: 80 / 4085

tabulation:	Freq.	Numeric	Label
	218	1	MAR 79
	219	2	APR 79
	195	3	MAY 79
	196	4	JUN 79
	174	5	JUL 79
	175	6	AUG 79
	162	7	SEP 79
	145	8	OCT 79
	155	9	NOV 79
	105	10	DEC 79
	196	11	JAN 80
	161	12	FEB 80
	145	13	MAR 80
	168	14	APR 80
	150	15	MAY 80
	122	16	JUN 80
	112	17	JUL 80
	107	18	AUG 80
	107	19	SEP 80
	85	20	OCT 80
	80	21	NOV 80
	75	22	DEC 80
	69	23	JAN 81
	51	24	FEB 81
	67	25	MAR 81
	66	26	APR 81
	31	27	MAY 81
	4	28	JUN 81
	5	29	JUL 81
	5	30	AUG 81
	5	31	SEP 81
	7	32	OCT 81
	6	33	NOV 81
	6	34	DEC 81
	5	35	JAN 82
	9	36	FEB 82
	4	37	MAR 82

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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5	38	APR 82
9	39	MAY 82
8	40	JUN 82
3	41	JUL 82
2	42	AUG 82
6	43	SEP 82
2	44	OCT 82
4	45	NOV 82
5	46	DEC 82
14	47	JAN 83
10	48	FEB 83
9	49	MAR 83
11	50	APR 83
11	51	MAY 83
7	52	JUN 83
11	53	JUL 83
7	54	AUG 83
4	55	SEP 83
7	56	OCT 83
14	57	NOV 83
6	58	DEC 83
8	59	JAN 84
9	60	FEB 84
8	61	MAR 84
10	62	APR 84
11	63	MAY 84
6	64	JUN 84
13	65	JUL 84
9	66	AUG 84
9	67	SEP 84
6	68	OCT 84
4	69	NOV 84
11	70	DEC 84
15	71	JAN 85
9	72	FEB 85
5	73	MAR 85
12	74	APR 85
9	75	MAY 85
7	76	JUN 85
9	77	JUL 85
4	78	AUG 85
5	79	SEP 85
6	80	OCT 85
3	81	NOV 85
11	82	DEC 85
8	83	JAN 86
2	84	FEB 86
2	85	MAR 86
6	86	APR 86
5	87	MAY 86
3	88	JUN 86
1	89	JUL 86
2	90	AUG 86
1	92	OCT 86

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SECTION 1.0 PATIENT ROSTER (CASE) INFORMATION

"RECORD" 9

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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3	93	NOV 86
5	94	DEC 86
5	95	JAN 87
7	96	FEB 87
7	97	MAR 87
2	98	APR 87

EPROTO ----- ENTRY PROTOCOL

type: numeric (float)  
label: EPROTO

range: [2,7] units: 1  
unique values: 6 coded missing: 0 / 4085

tabulation:	Freq.	Numeric	Label
	76	2	NEWBORN W CNTRL
	557	3	NEWBORN WO CNTRL
	292	4	PEDIATRIC < 2
	928	5	PEDIATRIC >= 2
	1038	6	ADOLESCENT
	1194	7	ADULT

ROSTER ----- ROSTER PATIENT

type: numeric (float)  
label: ROSTER

range: [1,2] units: 1  
unique values: 2 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	2246	1	YES
	1836	2	NO

RELATION ----- RELATION TO HEAD OF HOUSEHOLD

type: numeric (float)  
label: RELATION

range: [1,9] units: 1  
unique values: 9 coded missing: 45 / 4085

tabulation:	Freq.	Numeric	Label
	617	1	HEAD
	175	2	SPOUSE OF HEAD
	2691	3	CHILD OF HEAD
	20	4	ADOPTED CHILD
	60	5	STEP CHILD
	405	6	OTH. BLOOD RELATIVE
	25	7	OTH. RELATIVE
	43	8	NON RELATIVE
	4	9	DK

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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PTYPE ----- PROTOCOL TYPE DURING PHASE 1

type: numeric (float)  
label: PTYPE

range: [1,2] units: 1  
unique values: 2 coded missing: 0 / 4085

tabulation: Freq. Numeric Label  
3900 1 FULL PROTOCOL  
185 2 SEMI PROTOCOL

ENTRYAGE ----- AGE AT ENTRY (YRS)

type: numeric (float)

range: [0,77] units: 1  
unique values: 65 coded missing: 0 / 4085

mean: 13.6125  
std. dev: 12.6525

percentiles: 10% 25% 50% 75% 90%  
0 2 11 22 31

ELIGIBLE ----- NEWBORN ELIGIBLE FOR CONTROL

type: numeric (float)  
label: ELIGIBLE

range: [0,3] units: 1  
unique values: 4 coded missing: 3 / 4085

tabulation: Freq. Numeric Label  
3813 0 N.A.  
72 1 NOT ELIGIBLE  
145 2 ELIGIBLE  
52 3 NOT DETERMINED

REFERRED ----- NEWBORN IDENTIFIED OR REFERRED

type: numeric (float)  
label: REFERRED

range: [0,3] units: 1  
unique values: 4 coded missing: 3 / 4085

tabulation: Freq. Numeric Label  
3462 0 N.A.  
158 1 IDENTIFIED  
52 2 REFERRED  
410 3 NOT DETERMINED

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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PTYPE ----- PROTOCOL TYPE DURING PHASE 1

type: numeric (float)  
label: PTYPE

range: [1,2] units: 1  
unique values: 2 coded missing: 0 / 4085

tabulation: Freq. Numeric Label  
3900 1 FULL PROTOCOL  
185 2 SEMI PROTOCOL

CPROTO ----- CURRENT PROTOCOL

type: numeric (float)  
label: CPROTO

range: [3,7] units: 1  
unique values: 5 coded missing: 3 / 4085

tabulation: Freq. Numeric Label  
5 3 NEWBORN WO CNTRL  
84 4 PEDIATRIC < 2  
736 5 PEDIATRIC >= 2  
1153 6 ADOLESCENT  
2104 7 ADULT

ISFAMID ----- FAMILY ID PATIENT

type: numeric (float)  
label: ISFAMID

range: [0,1] units: 1  
unique values: 2 coded missing: 3 / 4085

tabulation: Freq. Numeric Label  
383 0 NOT THE FAMILY ID  
3699 1 FAMILY ID

G6PDEF ----- G-6-PD DEFICIENCY

type: numeric (float)  
label: G6PDEF

range: [1,2] units: 1  
unique values: 2 coded missing: 2388 / 4085

tabulation: Freq. Numeric Label  
174 1 G-6-PD DEFICIENT  
1523 2 NOT DEFICIENT

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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HASTUBE ----- DNA SAMPLE AT REPOSITORY?

type: numeric (float)  
label: HASTUBE  
  
range: [0,1] units: 1  
unique values: 2 coded missing: 1769 / 4085

tabulation:	Freq.	Numeric	Label
	232	0	NO
	2084	1	YES

IDCHANGE ----- CHANGED ID AND/OR CLINIC

type: numeric (float)  
label: IDCHANGE  
  
range: [0,1] units: 1  
unique values: 2 coded missing: 0 / 4085

tabulation:	Freq.	Numeric	Label
	3769	0	NO
	316	1	YES

INFLOAD ----- CYCLE # OF LATEST 16 OR 16E LOADED

type: numeric (float)  
  
range: [0,25] units: 1  
unique values: 26 coded missing: 3 / 4085

tabulation:	Freq.	Value
	3164	0
	5	1
	10	2
	5	3
	12	4
	14	5
	25	6
	15	7
	8	8
	10	9
	7	10
	8	11
	22	12
	19	13
	11	14
	25	15
	9	16
	32	17
	93	18
	53	19
	100	20
	288	21
	115	22

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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21 23  
10 24  
1 25

INF2 ----- INTAKE AT AGE 2 FORM FOR INFANTS

type: numeric (float)  
label: INF2

range: [0,9] units: 1  
unique values: 9 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3251	0	NOT REQUIRED
	627	1	LOADED
	25	2	NOT DONE
	49	3	REPORTED DONE
	13	5	DIED
	15	6	REFUSED
	19	7	MOVED
	17	8	LOST TO F.U.
	66	9	MISSING

INT1 ----- FIRST INTERIM CLINIC VISIT

type: numeric (float)  
label: INT1

range: [0,9] units: 1  
unique values: 10 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	527	0	NOT REQUIRED
	2928	1	LOADED
	229	2	NOT DONE
	22	3	REPORTED DONE
	13	4	SICK
	28	5	DIED
	161	6	REFUSED
	49	7	MOVED
	88	8	LOST TO F.U.
	37	9	MISSING

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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ANN1 ----- FIRST ANNUAL CLINIC VISIT

type: numeric (float)

label: ANN1

range: [0,9]

units: 1

unique values: 10

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	137	0	NOT REQUIRED
	3327	1	LOADED
	72	2	NOT DONE
	26	3	REPORTED DONE
	9	4	SICK
	52	5	DIED
	117	6	REFUSED
	95	7	MOVED
	105	8	LOST TO F.U.
	142	9	MISSING

ANN2 ----- SECOND ANNUAL CLINIC VISIT

type: numeric (float)

label: ANN2

range: [0,9]

units: 1

unique values: 10

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	217	0	NOT REQUIRED
	2991	1	LOADED
	135	2	NOT DONE
	10	3	REPORTED DONE
	19	4	SICK
	80	5	DIED
	176	6	REFUSED
	149	7	MOVED
	132	8	LOST TO F.U.
	173	9	MISSING

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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INT3 ----- THIRD INTERIM CLINIC VISIT

type: numeric (float)

label: INT3

range: [0,9]

units: 1

unique values: 10

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	829	0	NOT REQUIRED
	2305	1	LOADED
	170	2	NOT DONE
	23	3	REPORTED DONE
	18	4	SICK
	74	5	DIED
	204	6	REFUSED
	150	7	MOVED
	149	8	LOST TO F.U.
	160	9	MISSING

ANN4 ----- FOURTH ANNUAL CLINIC VISIT

type: numeric (float)

label: ANN4

range: [0,9]

units: 1

unique values: 10

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	439	0	NOT REQUIRED
	2566	1	LOADED
	18	2	NOT DONE
	13	3	REPORTED DONE
	3	4	SICK
	128	5	DIED
	176	6	REFUSED
	187	7	MOVED
	172	8	LOST TO F.U.
	380	9	MISSING

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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ANN5 ----- FIFTH ANNUAL CLINIC VISIT

type: numeric (float)  
label: ANN5  
  
range: [0,9] units: 1  
unique values: 10 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	506	0	NOT REQUIRED
	2324	1	LOADED
	1	2	NOT DONE
	18	3	REPORTED DONE
	1	4	SICK
	163	5	DIED
	139	6	REFUSED
	139	7	MOVED
	158	8	LOST TO F.U.
	633	9	MISSING

ANN6 ----- SIXTH ANNUAL CLINIC VISIT

type: numeric (float)  
label: ANN6  
  
range: [0,9] units: 1  
unique values: 9 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	604	0	NOT REQUIRED
	2026	1	LOADED
	5	3	REPORTED DONE
	3	4	SICK
	191	5	DIED
	99	6	REFUSED
	82	7	MOVED
	145	8	LOST TO F.U.
	927	9	MISSING

ANN7 ----- SEVENTH ANNUAL CLINIC VISIT

type: numeric (float)  
label: ANN7  
  
range: [0,9] units: 1  
unique values: 7 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	1764	0	NOT REQUIRED
	1453	1	LOADED
	213	5	DIED
	34	6	REFUSED
	35	7	MOVED
	119	8	LOST TO F.U.
	464	9	MISSING

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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ANN8 ----- EIGHTH ANNUAL CLINIC VISIT

type: numeric (float)  
label: ANN8  
  
range: [0,9] units: 1  
unique values: 7 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3219	0	NOT REQUIRED
	494	1	LOADED
	162	5	DIED
	9	6	REFUSED
	12	7	MOVED
	65	8	LOST TO F.U.
	121	9	MISSING

ANN9 ----- NINTH ANNUAL CLINIC VISIT

type: numeric (float)  
label: ANN9  
  
range: [0,1] units: 1  
unique values: 2 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	4054	0	NOT REQUIRED
	28	1	LOADED

MENSTAT ----- MENINGITIS

type: numeric (float)  
label: MENSTAT  
  
range: [0,3] units: 1  
unique values: 4 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3919	0	
	47	1	1ST MENINGITIS IN STUDY
	1	2	MENINGITIS BEFORE & IN STUDY
	115	3	MENINGITIS BEFORE STUDY

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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SEIZSTAT ----- SEIZURES

type: numeric (float)

label: SEIZSTAT

range: [0,3]

units: 1

unique values: 4

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3814	0	
	80	1	1ST SEIZURE IN STUDY
	15	2	SEIZURES BEFORE & IN STUDY
	173	3	SEIZURES BEFORE STUDY

CVASTAT ----- CEREBROVASCULAR ACCIDENT

type: numeric (float)

label: CVASTAT

range: [0,3]

units: 1

unique values: 4

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3838	0	
	91	1	1ST CVA IN STUDY
	25	2	CVA BEFORE & IN STUDY
	128	3	CVA BEFORE STUDY

ANSTAT ----- ASEPTIC NECROSIS

type: numeric (float)

label: ANSTAT

range: [0,2]

units: 1

unique values: 2

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3597	0	NO PROBLEMS
	485	2	CURRENT PROBLEM

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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SHOULDER ----- SHOULDER X-RAY STATUS

type: numeric (float)  
label: SHOULDER

range: [0,26] units: 1  
unique values: 10 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	897	0	NOT REQUIRED
	334	1	#1 NOT DONE
	101	2	#2 NOT DUE
	320	3	INACTIVE FOR #2
	699	4	#2 NOT DONE
	1605	5	#2 DONE
	39	20	CONTROL-NEED REP
	67	22	CONTROL-REP DONE
	12	25	CONTROL-INACTIVE
	8	26	CONTROL-AN LATER

HIP ----- HIP X-RAY STATUS

type: numeric (float)  
label: HIP

range: [0,26] units: 1  
unique values: 10 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	897	0	NOT REQUIRED
	362	1	#1 NOT DONE
	118	2	#2 NOT DUE
	305	3	INACTIVE FOR #2
	609	4	#2 NOT DONE
	1665	5	#2 DONE
	42	20	CONTROL-NEED REP
	66	22	CONTROL-REP DONE
	12	25	CONTROL-INACTIVE
	6	26	CONTROL-AN LATER

PFLMSTAT ----- PLAIN FILM OF ABDOMEN

type: numeric (float)  
label: PFLMSTAT

range: [0,6] units: 1  
unique values: 7 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	2474	0	NOT NEEDED
	148	1	NEED TEST
	12	2	REFUSED
	66	3	NOT DONE-INACTIVE
	172	4	CHOLECYSTECTOMY
	3	5	NOT DONE MED. REASON
	1207	6	DONE

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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SONOGRAM ----- SONOGRAM NEEDED

type: numeric (float)

label: SONOGRAM

range: [0,26]

units: 1

unique values: 18

coded missing: 3 / 4085

tabulation:

Freq.	Numeric	Label
3574	0	N.A.
53	1	NEED SONO #1
154	2	SONO #1 DONE
11	3	SONO NOT DONE, OC+
9	4	REPEAT PFLM +
14	5	INACTIVE BEF EXT.
10	6	SURG SINCE - PFLM
1	9	UNKNOWN-NO GS RESP.
102	10	N.A.-FIRST PFLM +
55	11	NEED REPEAT
37	12	REPEAT DONE
2	14	PFLM + AFT - SONO
8	15	INACTIVE AFT EXT
15	20	NEED SONO-YNG PT
30	22	SONO DONE-YNG PT
4	23	ND-GS IN PAST-YNG
2	24	CHOLECYST.-YNG PT
1	26	ND-REFUSED-YNG PT

SPLNSTAT ----- SPLEEN SCAN

type: numeric (float)

label: SPLNSTAT

range: [0,7]

units: 1

unique values: 6

coded missing: 3 / 4085

tabulation:

Freq.	Numeric	Label
3914	0	NOT NEEDED
37	3	NEEDED BUT MISSED
1	4	SCAN DONE TOO LATE
89	5	SCAN COMPLETED
10	6	SCAN NOT DONE
31	7	DISCONTINUED

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

OCEXSTAT ----- OCULAR EXAM STATUS

type: numeric (float)  
 label: OCEXSTAT

range: [0,3] units: 1  
 unique values: 4 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3728	0	NEVER CHOSEN
	111	1	TO BE EXAMINED
	75	2	CHOSEN BUT DELETED
	168	3	EXAM COMPLETE

PFTSTAT ----- PULMONARY FUNCTION TEST

type: numeric (float)  
 label: PFTSTAT

range: [0,16] units: 1  
 unique values: 9 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	2688	0	NOT NEEDED
	185	1	TEST NEEDED
	38	2	REFUSED TEST
	109	3	NOT DONE-INACTIVE
	16	4	NOT DONE MED. REASON
	2	5	? DONE, NO FORM RECD
	925	6	DONE
	1	15	REPORTED DONE-CARD.
	118	16	DONE-CARDIAC STUDY

CARDSTAT ----- CARDIOLOGY EVALUATION STATUS

type: numeric (float)  
 label: CARDSTAT

range: [0,16] units: 1  
 unique values: 13 coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3746	0	NOT REQUIRED
	59	1	#1 NOT DONE
	17	2	REFUSED #1
	14	3	INACT. FOR #1
	5	4	NO #1, MED. REASON
	1	5	? DONE, NO FORM RECD
	63	6	NEED STUDY #2
	1	11	NO #2, TRNSFRD
	1	12	REFUSED #2
	16	13	INACT. FOR #2
	1	14	NO #2, MED. REASON
	17	15	#2 REPORTED DONE
	141	16	#2 DONE

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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PSYSTAT ----- PSYCHOSOCIAL STUDY STATUS

type: numeric (float)

label: PSYSTAT

range: [0,6]

units: 1

unique values: 7

coded missing: 3 / 4085

tabulation:	Freq.	Numeric	Label
	3652	0	NOT NEEDED
	50	1	NOT DONE - GRP 1,3
	48	2	NOT DONE - GRP 2,4
	31	3	NOT DONE - GRP 5
	87	4	DONE - GRP 1,3
	93	5	DONE - GRP 2,4
	121	6	DONE - GRP 5

PENSTUDY ----- PAIN COMFORT MEASURES STUDY

type: numeric (float)

label: PENSTUDY

range: [0,9]

units: 1

unique values: 9

coded missing: 18 / 4085

tabulation:	Freq.	Numeric	Label
	3465	0	NOT REQUIRED
	112	1	NEED QUESTIONNAIRE
	420	2	QUESTIONNAIRE DONE
	9	3	DONE,NOT REQUIRED
	2	5	NOT DONE,DIED
	9	6	NOT DONE,REFUSED
	24	7	NOT DONE,MOVED
	18	8	NOT DONE,LTFU
	8	9	NOT DONE,NO REAS.

PNEUVAX ----- HAS PATIENT RECEIVED PNEUMOVAX

type: numeric (float)

label: PNEUVAX

range: [1,2]

units: 1

unique values: 2

coded missing: 2163 / 4085

tabulation:	Freq.	Numeric	Label
	1554	1	RECEIVED,CONFIRMED
	368	2	REC'D,NO CONF. RESP.

CODEBOOK FOR CSSCD 'RECORD' 9

PHASE 1 PATIENT ROSTER

CSSCD FULL COHORT PATIENTS

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STATUS ----- PATIENT STATUS AT END OF PHASE 1

type: numeric (float)  
label: STATUS

range: [1,5] units: 1  
unique values: 3 coded missing: 0 / 4085

tabulation: Freq. Numeric Label  
2769 1 ACTIVE  
1031 3 LOST TO FOLLOW-UP  
285 5 DEAD

PHASE2 ----- INFANT ENROLLED IN CSSCD PHASE 2

type: numeric (float)  
label: PHASE2

range: [0,1] units: 1  
unique values: 2 coded missing: 0 / 4085

tabulation: Freq. Numeric Label  
3618 0 NO  
467 1 YES

PHASE3 ----- INFANT ENROLLED IN CSSCD PHASE 3

type: numeric (float)  
label: PHASE3

range: [0,1] units: 1  
unique values: 2 coded missing: 0 / 4085

tabulation: Freq. Numeric Label  
3707 0 NO  
378 1 YES

PHASE2A ----- ADULT ENROLLED IN CSSCD PHASE 2

type: numeric (float)  
label: PHASE2A

range: [0,1] units: 1  
unique values: 2 coded missing: 0 / 4085

tabulation: Freq. Numeric Label  
3726 0 NO  
359 1 YES

\_dta:

1. Created 06/15/2001