

10.0: Other - Overview

1. Created 7/5/2000.

CSSCD Forms (collection) and Datasets (storage) Relating to Other Data

<u>Form #</u>	<u>Name of Form</u>	<u>Collected</u>	<u>Patient Population</u>	<u>SAS Dataset</u>
26	Supplement to Extension Annual Visit Form (Associated Medical Problems)	04/85 – 10/88	All at age \geq 2 years	R20.SD2
27	Life Status Form for Patients Not Seen for Exit Annual	07/86 – 07/88	Patients entered at \geq 6 months of age who were not seen for exit annual visit	R92.SD2

**10.1: Supplement to Extension Annual Visit Form
(Associated Medical Problems) – Form 26**

A. List of variables deleted **F20INIT F20NDATE F20LASTU F20LASTE
F20ESTAT F20VDATE F20DATE F20DFC F20FCB F20SITE F20AIDS
F20DOWNS F20IMP F20SYPH F20SCHIZ F20MANIA F20DPR F20ALC
F20DRUGS F20OTHL1 F20OTHN1 F20OTHL2 F20OTHN2 F20OTHL3
F20OTHN3**

B. List of variables modified **NONE**

C. List of variables modified with a name change **NONE**

D. Old name

E. New name

F. List of variables modified date to days since DOE

G. Old name **F20DATE**

H. New name **JF20DATE**

I. Collection Information:

Form 26 (Supplement to Extension Annual Visit Form) was to be filled out at the time of the 1985 annual visit for all patients who were 2 years of age or older by the physician or nurse most familiar with the patient's history. The form was completed at the time of a later annual visit for the some patients who missed a visit in 1985 and for patients who turned two after 1985. The form was designed to collect information about non-SCD-related medical conditions that the patient had since study entry. Although only one form per patient was required, more than one form was submitted for some patients. Consequently, multiple forms per patient may be in the dataset.

J. Data Collection Period: 04/85 – 09/88

K. Form Version Dates: 03/17/85

L. Files Used to Store Information:

SAS System File: **R20.SD2**

Format File: **R20.FMT**

M. Unique Record Identifiers: **ANONID, F20CYCLE**

Records within the dataset are sorted by **ANONID** and **F20CYCLE**.

N. Number of Patients (Observations) in SAS Dataset: 3441 (2876)

O. Contents of SAS Dataset:

**10.1: Supplement to Extension Annual Visit Form
(Associated Medical Problems) – Form 26**

- Alphabetical Listing of Variables: See pp. 7-9
- Listing of Variables by Position: See pp. 10-11

P. Notes About Selected Variables:

- **F20SOLID** – is the variable name for solid tumor. A “yes” response is non-specific with respect to whether the tumor was malignant.
- **F20OHL1-3** – are variable names for ICD-9 codebook diagnosis letter codes. These letter codes are used in conjunction with the ICD-9 disease number code variables (**F20OHN1-3**).

Q. Computed Variables: None

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R. Inter-Relationship With Other Datasets:

- Sources which collect information related to on-study medical conditions/organ function are

Phase 1 Form	SAS Dataset
"Iron-Lead"	R08.SD2
Form 11	R1121.SD2
Forms 12, 22	R1222.SD2
Form 14	R14.SD2
Form 15	R15.SD2
Form 16	R16.SD2
Forms 17, 19, 20, 21, 24	R1722.SD2
Form 25	R25.SD2
Form 34	R34.SD2
Form 46	R46.SD2
Form 50	R50.SD2
Form 50E	R80.SD2
Form 53	R53.SD2
Form 62	R62.SD2
Form 70	R70.SD2
Form 71	R71.SD2
Form 75	R75.SD2
Form 82	R82.SD2
Form 84	R84.SD2
Form 90	R90.SD2
Form 94	R94.SD2
Form 94E	R96.SD2
Form 98	R98.SD2
Form 99	R97.SD2, R99.SD2

**10.1: Supplement to Extension Annual Visit Form
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<u>Disease Category</u>	<u>Form #</u>	<u>SAS Dataset</u>	<u>Type of Information Collected</u>	<u>For Relevant Variables, See Section</u>
Sarcoidosis	94E	R96.SD2		6.8
Autoimmune Hemolytic Anemia	14	R14.SD2	Coombs' test results during neonatal period	2
	15	R15.SD2	Coombs' test result during neonatal period	2
	16	R16.SD2	Coombs' test results at time of infant interim visit	4
	46	R46.SD2	Coombs' test results at time of AAE	7.6
	53	R53.SD2	Coombs' test results at time of AAE	7.9
	84	R84.SD2	On-study transfusion data	9.2
Hepatitis	34	R34.SD2	Hx of contact with infected person at time of RUQ event, hepatitis B surface antigen/antibody results	7.3
	53	R53.SD2	Hepatitis diagnosed at time of RUQ event	7.9
Hypertension	11, 17, 19, 20, 21, 24	R1121.SD2	Steady-state BP readings	4
		R1722.SD2	Steady-state BP readings, use of BP medications	4
	25	R25.SD2	Steady-state BP readings, use of BP medications	4
	62	R62.SD2	BP readings at time of renal event	8.1
	70	R70.SD2	BP readings at time of f/u for UTI or hematuria	8.1
	71	R71.SD2	BP readings at time of f/u for proteinuria or renal insufficiency	8.1
	82	R82.SD2	BP readings at time of pregnancy visit	9.4
	98	R98.SD2	BP readings at time of cardiac evaluation, hx of high BP	6.9

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<u>Disease Category</u>	<u>Form #</u>	<u>SAS Dataset</u>	<u>Type of Information Collected</u>	<u>For Relevant Variables, See Section</u>
Other Cardiovascular Disorders/	98	R98.SD2	History of cardiac problems, cardiac physical findings	6.9
Cardiovascular Function	99	R99.SD2	ECG/ECHO findings	6.9
	99	R97.SD2	Cardiac findings during exercise	6.9

Note: All routine visit forms collect limited steady-state cardiac exam data (Forms 11, 17, 19, 20, 21, 24, 25; See Section 4)

Respiratory Disorders/ Pulmonary Function	75	R75.SD2	Routine chest x-ray findings	6.3
	82	R82.SD2	Lung exam findings during pregnancy	9.4
	94	R94.SD2	Pulmonary function test results	6.8
	94E	R96.SD2	History or pulmonary disease (bronchitis, asthma, TB, etc.)	6.8
	99	R97.SD2	Oxygen consumption/CO ₂ production during exercise	6.9

Note: All routine visit forms collect limited steady-state pulmonary physical findings (Forms 11, 17, 19, 20, 21, 24, 25; See Section 4).

For data collected at the time of on-study acute chest events, see Forms 32, 32E, and 53 (sections 7.2 and 7.9).

Lead Poisoning	--	R08.SD2	History of pica, lead level	5.3
Impotence	50	R50.SD2	History of impotence at time of priapism event	7.8
	50E	R80.SD2	History of impotence at time of priapism event	7.8
	57	R57.SD2	History of impotence at time of f/u for acute priapism	7.8

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(Associated Medical Problems) – Form 26**

<u>Disease Category</u>	<u>Form #</u>	<u>SAS Dataset</u>	<u>Type of Information Collected</u>	<u>For Relevant Variables, See Section</u>
Renal Disorders/Renal Function	12, 22	R1222.SD2	Steady-state U/A, urine culture, BUN, serum creatinine, uric acid	4
	17, 19, 20, 24	R1722.SD2	Steady-state U/A, urine culture, BUN, serum creatinine, uric acid	4
	25	R25.SD2	Steady-state U/A, serum creatinine	4
	62	R62.SD2	History, P.E. findings, lab work done at time of renal event (UTI, hematuria, proteinuria, renal insufficiency)	8.1
	70	R70.SD2	History, P.E. findings, lab work done at time of f/u for UTI or hematuria	8.1
	71	R71.SD2	History, P.E. findings, lab work done at time of f/u for proteinuria, renal insufficiency	8.1
	82	R82.SD2	U/A, urine culture results at time of pregnancy visit	9.4
Substance Abuse	94E	R96.SD2	Smoking history of patients who had PFTs done	6.8
	98	R98.SD2	Smoking/drinking habits of patients who had full cardiac evaluation	6.9
	82	R82.SD2	Smoking/drinking habits during pregnancy	9.4
All Non-SCD-Related Hospitalizations	90	R90.SD2	Reason for hospitalization	9.3

- Data regarding pre-entry non-SCD-related medical problems were collected on the Past Medical History forms (Forms 10 and 15; See Section 2).
- Coincidental and non-SCD-related problems may also be reported in the final diagnosis section of 1) the Acute Event Treatment Follow-up form (Form 52; See Section 7.10), 2) the Painful Episode/Skeletal & Joint Event Flow Sheet & Treatment Follow-up form (Form 31; See Section 7.1.3), or 3) the Acute Chest Syndrome Flow Sheet form (Form 33; See Section 7.2.3).

CODEBOOK FOR CSSCD FORM 26
SUPPLEMENT TO EXTENSION ANNUAL VISIT FORM
 CSSCD FULL COHORT PATIENTS

CONTENTS OF SAS DATASET: R20.SD2
 DATA FROM CSSCD FORM 26 - SUPPLEMENT TO EXTENSION ANNUAL VISIT FORM
 (ASSOCIATED MEDICAL PROBLEMS)
 VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
 IN THE SAS DATASET AND ON FORM 26
 The SAS System 14:00 Wednesday, February 21, 2007 8

The CONTENTS Procedure

Data Set Name	OUT1.R20	Observations	3441
Member Type	DATA	Variables	47
Engine	V9	Indexes	0
Created	10:39 Friday, February 16, 2007	Observation Length	376
Last Modified	10:39 Friday, February 16, 2007	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	81
First Data Page	1
Max Obs per Page	43
Obs in First Data Page	26
Number of Data Set Repairs	0
File Name	r20.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
21	F20AHD	Num	8	ATHEROSCLEROTIC HEART DISEASE
12	F20AIHA	Num	8	AUTOIMMUNE HEMOLYTIC ANEMIA
13	F20AIHAT	Num	8	HAS AIHA - TRANSFUSED IN PAST
3	F20ALL	Num	8	ACUTE LYMPHOCYTIC LEUKEMIA
4	F20AML	Num	8	ACUTE MYELOCYTIC LEUKEMIA
23	F20ARF	Num	8	ACUTE RHEUMATIC FEVER
24	F20ARFH	Num	8	ACUTE RHEUMATIC FEVER W HEART DISEASE
35	F20ARTHR	Num	8	RHEUMATOID ARTHRITIS
27	F20ASTH	Num	8	ASTHMA
42	F20BIOP	Num	8	RENAL BIOPSY DIAGNOSIS
29	F20BRON	Num	8	CHRONIC BRONCHITIS
25	F20CERAN	Num	8	CEREBRAL ANEURYSM
22	F20CHD	Num	8	CONGENITAL HEART DISEASE
5	F20CLL	Num	8	CHRONIC LYMPHOCYTIC LEUKEMIA
6	F20CML	Num	8	CHRONIC MYELOCYTIC LEUKEMIA
33	F20COL	Num	8	ULCERATIVE COLITIS
44	F20CPS	Num	8	CHRONIC PAIN SYNDROME

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32	F20CROHN	Num	8	CROHNS DISEASE
2	F20CYCLE	Num	8	CYCLE
36	F20DIAB	Num	8	DIABETES MELLITUS
28	F20EMPH	Num	8	EMPHYSEMA
38	F20ENUR	Num	8	ENURESIS
41	F20ESRD	Num	8	END STAGE RENAL DISEASE
8	F20HD	Num	8	HODGKINS DISEASE
43	F20HEMO	Num	8	HEMODIALYSIS
14	F20HEP	Num	8	HEPATITIS
15	F20HEPA	Num	8	HEPATITIS-TYPE A
16	F20HEPB	Num	8	HEPATITIS-TYPE B
18	F20HEPCM	Num	8	HEPATITIS-CMV
17	F20HEPN	Num	8	HEPATITIS-TYPE NON-A NON-B
19	F20HYP	Num	8	HYPERTENSION
11	F20ITP	Num	8	IDIOPATHIC THROMBOCYTOPENIC PURPURA
39	F20LEAD	Num	8	LEAD POISONING
20	F20MI	Num	8	MYOCARDIAL INFARCTION
7	F20NHL	Num	8	NON-HODGKINS LYMPHOMA
46	F20OTHER	Num	8	OTHER ASSOCIATED PROBLEM
26	F20PHYP	Num	8	PULMONARY HYPERTENSION
40	F20RTRAN	Num	8	RENAL TRANSPLANT
9	F20SARC	Num	8	SARCOIDOSIS
34	F20SLE	Num	8	SYSTEMIC LUPUS ERYTHEMATOSUS
45	F20SMOKE	Num	8	CIGARETTE SMOKING
10	F20SOLID	Num	8	SOLID TUMORS
30	F20TB	Num	8	TUBERCULOSIS
37	F20THYR	Num	8	THYROID DISEASE
31	F20ULC	Num	8	GASTRIC OR DUODENAL ULCER
47	JF20DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

CODEBOOK FOR CSSCD FORM 26
SUPPLEMENT TO EXTENSION ANNUAL VISIT FORM
CSSCD FULL COHORT PATIENTS

* R20.FMT contains value labels for numerical codes assigned to categorical*
* variables in the SAS dataset R20.SD2 *
*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 06/11/99 11:35:45;

PROC FORMAT;

*FORMAT NO_YES used for the following variables: F20ALL F20AML
F20CLL F20CML
F20NHL F20HD
F20SARC F20SOLID
F20ITP F20AIHA
F20AIHAT
F20HEP F20HEPA
F20HEPB F20HEPN
F20HEPCM F20HYP
F20MI F20AHD
F20CHD F20ARF
F20ARFH F20CERAN
F20PHYP F20ASTH
F20EMPH F20BRON
F20TB F20ULC
F20CROHN F20COL
F20SLE F20ARTHR
F20DIAB F20THYR
F20ENUR F20LEAD
F20RTRAN
F20ESRD F20HEMO
F20CPS F20SMOKE
F20OTHER;

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

VALUE F20BIOP
-1 = 'NOT DONE';

* FORMAT F20ALL F20AML
F20CLL F20CML
F20NHL F20HD
F20SARC F20SOLID
F20ITP F20AIHA
F20AIHAT
F20HEP F20HEPA
F20HEPB F20HEPN
F20HEPCM F20HYP
F20MI F20AHD
F20CHD F20ARF
F20ARFH F20CERAN

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F20PHYP F20ASTH
F20EMPH F20BRON
F20TB F20ULC
F20CROHN F20COL
F20SLE F20ARTHR
F20DIAB F20THYR
F20ENUR F20LEAD
F20RTRAN
F20ESRD F20HEMO
F20CPS F20SMOKE
F20OTHER NO_YES.
F20BIOP F20BIOP.;

RUN;
QUIT;

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F20CYCLE ----- CYCLE

type: numeric (float)
 range: [1,44] units: 1
 unique values: 16 coded missing: 0 / 3441

tabulation: Freq. Value	tabulation: Freq. Value
1 1	169 33
1 3	4 34
135 25	778 35
1 26	1292 37
127 27	574 39
2 28	191 41
71 29	10 43
84 31	1 44

F20VDATE ----- VERSION DATE

DELETED

type: numeric daily date (float)
 label: datelab
 range: [9207,9207] units: 1
 or equivalently: [17mar1985,17mar1985] units: days
 unique values: 1 coded missing: 0 / 3441

tabulation: Freq. Numeric Label
3441 9207 03/17/85

F20ALL ----- ACUTE LYMPHOCYTIC LEUKEMIA

type: numeric (float)
 label: F20ALL
 range: [1,1] units: 1
 unique values: 1 coded missing: 0 / 3441

tabulation: Freq. Numeric Label
3441 1 NO

F20AML ----- ACUTE MYELOCYTIC LEUKEMIA

type: numeric (float)
 label: F20AML
 range: [1,1] units: 1
 unique values: 1 coded missing: 0 / 3441

tabulation: Freq. Numeric Label
3441 1 NO

F20CLL ----- CHRONIC LYMPHOCYTIC LEUKEMIA

type: numeric (float)
 label: F20CLL
 range: [1,1] units: 1
 unique values: 1 coded missing: 0 / 3441

tabulation: Freq. Numeric Label
3441 1 NO

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F20CML ----- CHRONIC MYELOCYTIC LEUKEMIA

type: numeric (float)
 label: F20CML
 range: [1,2] units: 1
 unique values: 2 coded missing: 0 / 3441

tabulation:	Freq.	Numeric	Label
	3440	1	NO
	1	2	YES

F20NHL ----- NON-HODGKINS LYMPHOMA

type: numeric (float)
 label: F20NHL
 range: [1,1] units: 1
 unique values: 1 coded missing: 0 / 3441

tabulation:	Freq.	Numeric	Label
	3441	1	NO

F20HD ----- HODGKINS DISEASE

type: numeric (float)
 label: F20HD
 range: [1,2] units: 1
 unique values: 2 coded missing: 0 / 3441

tabulation:	Freq.	Numeric	Label
	3439	1	NO
	2	2	YES

F20SARC ----- SARCOIDOSIS

type: numeric (float)
 label: F20SARC
 range: [1,2] units: 1
 unique values: 2 coded missing: 0 / 3441

tabulation:	Freq.	Numeric	Label
	3435	1	NO
	6	2	YES

F20SOLID ----- SOLID TUMORS

type: numeric (float)
 label: F20SOLID
 range: [1,2] units: 1
 unique values: 2 coded missing: 4 / 3441

tabulation:	Freq.	Numeric	Label
	3428	1	NO
	9	2	YES

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F2OSITE ----- SOLID TUMOR SITE DELETED

type: numeric (float)
 label: F2OSITE
 range: [4,256] units: 1
 unique values: 7 coded missing: 3432 / 3441

tabulation:	Freq.	Numeric	Label
		1	BRAIN
		2	LUNG
	1	4	BREAST
	1	8	GI
	1	16	KIDNEY
		32	PROSTATE
	3	64	UTERUS-CERVIX
	1	128	EXTREMITIES
	1	132	
	1	256	OTHER

F2OSITE:

1. Binary coded variable. See Part II for explanation of binary coded variables.
2. Required only if F2OSOLID=2.

F2OITP ----- IDIOPATHIC THROMBOCYTOPENIC PURPURA

type: numeric (float)
 label: F2OITP
 range: [1,1] units: 1
 unique values: 1 coded missing: 1 / 3441

tabulation:	Freq.	Numeric	Label
	3440	1	NO

F2OAIHA ----- AUTOIMMUNE HEMOLYTIC ANEMIA

type: numeric (float)
 label: F2OAIHA
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3420	1	NO
	19	2	YES

F2OAIHAT ----- HAS AIHA - TRANSFUSED IN PAST

type: numeric (float)
 label: F2OAIHAT
 range: [1,2] units: 1
 unique values: 2 coded missing: 732 / 3441

tabulation:	Freq.	Numeric	Label
	2690	1	NO
	19	2	YES

F2OAIHAT:

1. Required only if F2OAIHA=2.

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F20AIDS ----- ACQUIRED IMMUNE DEFICIENCY SYNDROME DELETED

```

      type: numeric (float)
      label: F20AIDS
      range: [1,2]
      unique values: 2
      tabulation: Freq.  Numeric  Label
                  3433      1  NO
                  4         2  YES
    
```

units: 1
coded missing: 4 / 3441

F20HEP ----- HEPATITIS

```

      type: numeric (float)
      label: F20HEP
      range: [1,2]
      unique values: 2
      tabulation: Freq.  Numeric  Label
                  3367      1  NO
                  73       2  YES
    
```

units: 1
coded missing: 1 / 3441

F20HEPA ----- HEPATITIS-TYPE A

```

      type: numeric (float)
      label: F20HEPA
      range: [1,2]
      unique values: 2
      tabulation: Freq.  Numeric  Label
                  2157      1  NO
                  12       2  YES
    
```

units: 1
coded missing: 1272 / 3441

F20HEPA:

1. Required only if F20HEP=2.

F20HEPB ----- HEPATITIS-TYPE B

```

      type: numeric (float)
      label: F20HEPB
      range: [1,2]
      unique values: 2
      tabulation: Freq.  Numeric  Label
                  2120      1  NO
                  39       2  YES
    
```

units: 1
coded missing: 1282 / 3441

F20HEPB:

1. Required only if F20HEP=2.

F20HEPN ----- HEPATITIS-TYPE NON-A NON-B

```

      type: numeric (float)
      label: F20HEPN
      range: [1,2]
      unique values: 2
      tabulation: Freq.  Numeric  Label
                  2116      1  NO
                  35       2  YES
    
```

units: 1
coded missing: 1290 / 3441

F20HEPN:

1. Required only if F20HEP=2.

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F2OHEPCM ----- HEPATITIS-CMV

type: numeric (float)
label: F2OHEPCM

range: [1,2] units: 1
unique values: 2 coded missing: 1296 / 3441

tabulation:	Freq.	Numeric	Label
	2143	1	NO
	2	2	YES

F2OHEPCM:

1. Required only if F2OHEP=2.

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F20HYP ----- HYPERTENSION

type: numeric (float)
 label: F20HYP
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3354	1	NO
	85	2	YES

F20MI ----- MYOCARDIAL INFARCTION

type: numeric (float)
 label: F20MI
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3436	1	NO
	3	2	YES

F20AHD ----- ATHEROSCLEROTIC HEART DISEASE

type: numeric (float)
 label: F20AHD
 range: [1,2] units: 1
 unique values: 2 coded missing: 5 / 3441

tabulation:	Freq.	Numeric	Label
	3422	1	NO
	14	2	YES

F20CHD ----- CONGENITAL HEART DISEASE

type: numeric (float)
 label: F20CHD
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3433	1	NO
	6	2	YES

F20ARF ----- ACUTE RHEUMATIC FEVER

type: numeric (float)
 label: F20ARF
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3421	1	NO
	18	2	YES

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F20ARFH ----- ACUTE RHEUMATIC FEVER W HEART DISEASE

type: numeric (float)
 label: F20ARFH
 range: [1,2] units: 1
 unique values: 2 coded missing: 400 / 3441

tabulation:	Freq.	Numeric	Label
	3034	1	NO
	7	2	YES

F20CERAN ----- CEREBRAL ANEURYSM

type: numeric (float)
 label: F20CERAN
 range: [1,2] units: 1
 unique values: 2 coded missing: 3 / 3441

tabulation:	Freq.	Numeric	Label
	3429	1	NO
	9	2	YES

F20PHYP ----- PULMONARY HYPERTENSION

type: numeric (float)
 label: F20PHYP
 range: [1,2] units: 1
 unique values: 2 coded missing: 3 / 3441

tabulation:	Freq.	Numeric	Label
	3434	1	NO
	4	2	YES

F20ASTH ----- ASTHMA

type: numeric (float)
 label: F20ASTH
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3343	1	NO
	96	2	YES

F20EMPH ----- EMPHYSEMA

type: numeric (float)
 label: F20EMPH
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3434	1	NO
	5	2	YES

CODEBOOK FOR CSSCD FORM 26
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 CSSCD FULL COHORT PATIENTS

F20BRON ----- CHRONIC BRONCHITIS

type: numeric (float)
 label: F20BRON
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3406	1	NO
	33	2	YES

F20TB ----- TUBERCULOSIS

type: numeric (float)
 label: F20TB
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3423	1	NO
	16	2	YES

F20ULC ----- GASTRIC OR DUODENAL ULCER

type: numeric (float)
 label: F20ULC
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3380	1	NO
	59	2	YES

F20CROHN ----- CROHNS DISEASE

type: numeric (float)
 label: F20CROHN
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3437	1	NO
	2	2	YES

F20COL ----- ULCERATIVE COLITIS

type: numeric (float)
 label: F20COL
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3436	1	NO
	3	2	YES

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F20SLE ----- SYSTEMIC LUPUS ERYTHEMATOSUS

type: numeric (float)
 label: F20SLE
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3434	1	NO
	5	2	YES

F20ARTHR ----- RHEUMATOID ARTHRITIS

type: numeric (float)
 label: F20ARTHR
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3414	1	NO
	25	2	YES

F20DIAB ----- DIABETES MELLITUS

type: numeric (float)
 label: F20DIAB
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3426	1	NO
	13	2	YES

F20THYR ----- THYROID DISEASE

type: numeric (float)
 label: F20THYR
 range: [1,2] units: 1
 unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3424	1	NO
	15	2	YES

F20ENUR ----- ENURESIS

type: numeric (float)
 label: F20ENUR
 range: [1,2] units: 1
 unique values: 2 coded missing: 5 / 3441

tabulation:	Freq.	Numeric	Label
	3285	1	NO
	151	2	YES

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F20LEAD ----- LEAD POISONING

type: numeric (float)
label: F20LEAD

range: [1,2] units: 1
unique values: 2 coded missing: 2 / 3441

tabulation:	Freq.	Numeric	Label
	3425	1	NO
	14	2	YES

F20DOWNS ----- DOWNS OR OTHER CHROMOSOME ABN.

DELETED

type: numeric (float)
label: F20DOWNS

range: [1,2] units: 1
unique values: 2 coded missing: 4 / 3441

tabulation:	Freq.	Numeric	Label
	3434	1	NO
	3	2	YES

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F20BIOP ----- RENAL BIOPSY DIAGNOSIS

type: numeric (float)
 label: F20BIOP
 range: [-1,996.8] units: .1
 unique values: 6 coded missing: 3425 / 3441

tabulation:	Freq.	Numeric	Label
	11	-1	NOT DONE
	1	582.2	
	1	590.2	
	1	591	
	1	710	
	1	996.8	

F20BIOP:

1. Required only if F20ESRD=2.
2. See ICD-9-CM Codebook for diagnosis codes.

F20HEMO ----- HEMODIALYSIS

type: numeric (float)
 label: F20HEMO
 range: [1,2] units: 1
 unique values: 2 coded missing: 2171 / 3441

tabulation:	Freq.	Numeric	Label
	1258	1	NO
	12	2	YES

F20HEMO:

1. Required only if F20ESRD=2.

F20SCHIZ ----- SCHIZOPHRENIA

DELETED

type: numeric (float)
 label: F20SCHIZ
 range: [1,2] units: 1
 unique values: 2 coded missing: 3 / 3441

tabulation:	Freq.	Numeric	Label
	3431	1	NO
	7	2	YES

F20MANIA ----- MANIA

DELETED

type: numeric (float)
 label: F20MANIA
 range: [1,2] units: 1
 unique values: 2 coded missing: 3 / 3441

tabulation:	Freq.	Numeric	Label
	3436	1	NO
	2	2	YES

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F20DEPR ----- DEPRESSION DELETED

type: numeric (float)
 label: F20DEPR
 range: [1,2] units: 1
 unique values: 2 coded missing: 3 / 3441

tabulation:	Freq.	Numeric	Label
	3326	1	NO
	112	2	YES

F20CPS ----- CHRONIC PAIN SYNDROME

type: numeric (float)
 label: F20CPS
 range: [1,2] units: 1
 unique values: 2 coded missing: 4 / 3441

tabulation:	Freq.	Numeric	Label
	3379	1	NO
	58	2	YES

F20ALC ----- ALCOHOLISM DELETED

type: numeric (float)
 label: F20ALC
 range: [1,2] units: 1
 unique values: 2 coded missing: 7 / 3441

tabulation:	Freq.	Numeric	Label
	3392	1	NO
	42	2	YES

F20SMOKE ----- CIGARETTE SMOKING

type: numeric (float)
 label: F20SMOKE
 range: [1,2] units: 1
 unique values: 2 coded missing: 7 / 3441

tabulation:	Freq.	Numeric	Label
	3018	1	NO
	416	2	YES

F20DRUGS ----- DRUG ADDICTION DELETED

type: numeric (float)
 label: F20DRUGS
 range: [1,2] units: 1
 unique values: 2 coded missing: 8 / 3441

tabulation:	Freq.	Numeric	Label
	3403	1	NO
	30	2	YES

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F200THER ----- OTHER ASSOCIATED PROBLEM

type: numeric (float)
 label: F200THER
 range: [1,2] units: 1
 unique values: 2 coded missing: 17 / 3441
 tabulation: Freq. Numeric Label
 3281 1 NO
 143 2 YES

F200THL1 ----- OTHER DISEASE LETTER CODE 1

DELETED

type: string (str1)
 unique values: 1 coded missing: 3440 / 3441
 tabulation: Freq. Value
 1 "D"

F200THL1:

1. See ICD-9 Codebook for letter codes.

F200THN1 ----- OTHER DISEASE NUMBER CODE 1

DELETED

type: numeric (float)
 range: [43.6,999.99] units: .01
 unique values: 116 coded missing: 3281 / 3441

tab:	Freq.	Value	tab:	Freq.	Value	tab:	Freq.	Value	tab:	Freq.	Value
	2	43.6		1	348.3		2	463		1	727.43
	1	71.02		1	360.43		2	465.9		1	729.81
	1	74.99		1	361.31		1	474		1	730.2
	1	78.1		1	362.1		1	518.8		1	733.42
	2	84.6		1	362.81		1	521		2	733.9
	1	97.1		1	365.23		1	541		1	737.3
	2	201.9		1	369.11		1	553.1		1	746.89
	1	250		1	373.9		1	553.2		1	748.5
	1	259.9		1	377.49		1	564		1	757.1
	2	274		1	379.9		1	574.1		2	759.8
	1	274.9		1	382.9		2	574.2		1	764.9
	1	275		1	389.12		2	577		4	780.3
	2	276.9		1	389.9		1	581.9		1	780.4
	1	277		2	396.9		1	583.9		1	780.6
	3	278		1	401.9		1	593.9		1	780.9
	7	282.6		1	402.9		1	599		1	783
	1	282.62		1	413.9		1	599.7		2	783.4
	1	289.3		1	416		1	599.79		2	784
	1	301.89		1	427.89		1	603.9		2	785.6
	1	308.9		3	428		2	607.3		1	786.09
	1	311		1	429.3		1	611.01		1	787
	2	317		1	435.9		1	614.9		1	789
	1	318.1		7	436		2	620.2		1	789.1
	5	319		1	438		1	620.9		1	791
	1	324		1	451.2		1	625.3		1	791.1
	1	331.9		1	451.89		1	709.9		1	791.91
	2	340		1	451.9		1	715.9		1	795.7
	1	343.9		1	461.9		1	719.41		1	999.8
	1	346.9		1	462		3	724.2		1	999.99

F200THN1:

1. Required only if F200THER=2
2. See ICD-9-CM codebook for diagnosis codes

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F200THL2 ----- OTHER DISEASE LETTER CODE 2 **DELETED**

type: string (str1)
 unique values: 0 coded missing: 3441 / 3441
 tabulation: Freq. Value

F200THL2:
 1. See ICD-9 Codebook for letter codes.

F200THN2 ----- OTHER DISEASE NUMBER CODE 2 **DELETED**

type: numeric (float)
 range: [3.9,789.1] units: .01
 unique values: 33 coded missing: 3408 / 3441

tab: Freq. Value

1	3.9
1	47
1	51.22
1	66.39
1	84.15
1	131.01
1	217
1	239.5
1	274.9

tab: Freq. Value

1	278
1	282.62
1	290.1
1	304.9
1	438
1	473.9
1	478.1
1	571.5

tab: Freq. Value

1	574.2
1	583.81
1	595.9
1	596.3
1	599
1	692.9
1	696.1
1	707.1

tab: Freq. Value

1	729.5
1	733.9
1	780.3
1	780.6
1	782.2
1	787
1	789
1	789.1

10.2: Life Status Form For Patients Not Seen For Exit Annual – Form 27

F200THN2:

1. Required only if F200THER=2
2. See ICD-9-CM codebook for diagnosis codes

F200THL3 ----- OTHER DISEASE LETTER CODE 3

DELETED

 type: string (str1)
unique values: 0 coded missing: 3441 / 3441
 tabulation: Freq. Value

F200THL3:

1. See ICD-9 Codebook for letter codes.

F200THN3 ----- OTHER DISEASE NUMBER CODE 3

DELETED

 type: numeric (float)
 range: [31.1,616.1] units: .01
unique values: 10 coded missing: 3430 / 3441
 tabulation: Freq. Value
 1 31.1
 1 65.29
 1 67.2
 1 282.6
 1 428

A. 1 589.1 List of variables deleted **F92INIT**

**F92NDATE F92LASTU F92LASTE F92ESTAT F92VDATE F92DFC F92FCB
F92DTH1 F92MVEMO F92MVEYR F92STATE F92DTH2 F92LSTMO
F92LSTYR**

B. List of variables modified **F92PMOVE F92PALIV**

C. List of variables modified with a name change **NONE**

D. Old name

E. New name

F. List of variables modified date to days since DOE

G. Old name **F92DTH1 F92DTH2**

H. New name **JF92DTH1 JF92DTH2**

I. Collection Information:

Form 27 (Life Status Form For Patients Not Seen For Exit Annual) was designed as an alternative exit form for patients entered at ≥ 6 months of age who were not seen for the required exit annual visit which was to be done between 06/01/86 and 06/01/87. In fact, the exit period was extended through 07/15/88. Clinic personnel were instructed to complete Form 27 for any patient who was not scheduled for an exit exam visit during his/her entry anniversary month between 06/01/86 and 06/01/87. However, if the patient was seen after a Form 27 was completed and before 07/15/88, an exit annual visit form (Form 25) was to be

10.2: Life Status Form For Patients Not Seen For Exit Annual – Form 27

completed. Consequently, both a Form 27 and a Form 25 with dates falling between 06/01/86 and 07/15/88 may be on the database. The purpose of the form was to collect information regarding the reason patient was not seen for an exit annual visit and to determine the date the patient was last known to be alive.

J. Data Collection Period: 06/86 – 07/88

K. Form Version Dates: 07/01/86

L. Files Used to Store Information:

SAS System File: **R92.SD2**

Format File: **R92.FMT**

M. Unique Record Identifiers: **ANONID, F92CYCLE**

Although only one Form 27 was required, a maximum of 2 records/case was allowed. Consequently, more than one “Record 92”/patient may be in the dataset. Records within the dataset are sorted by **ANONID** and **F92CYCLE**.

N. Number of Observations (Patients) in SAS Dataset: 1162 (1161)

O. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See p. 30
- Listing of Variables by Position: See p. 31

P. Notes About Selected Variables: None

Q. Computed Variables: None

R. Inter-Relationship With Other Datasets:

1. Summary variables related to change in patient status and status of routine follow-up visits during the study are contained in the “patient roster” dataset (**R09.SD2**). See explanations in Section 1 for the following variables:

STATUS

STATUSD

LASTSEEN

Routine follow-up visit status variables (**INF2, INT1, ANN1, ANN2, INT3, ANN3, ANN4, ANN5, ANN7, ANN8**)

2. The Extension Annual Clinic Visit Form (Form 25, **R25.SD2**) was used as the exit form for the majority of patients entered at ≥ 6 months of age [See Section 4].

10.2: Life Status Form For Patients Not Seen For Exit Annual – Form 27

The Life Status form (Form 27) was not required for any patient who was seen for a routine clinic visit [Form 25 completed] during the exit period (06/01/86 – 07/15/88). However, there are some patients who have both a Form 27 and a Form 25 on the database during the exit period.

3. The following datasets collect information relating to on-study deaths:

R09.SD2 (Variables **STATUS** & **STATUSD**)

R89.SD2

R91.SD2

R93.SD2

Although death is included as a reason for not being seen on the Life Status form, the form was not completed for the majority of patients who died since there were other collection sources used for reporting this event. Selection of patients with **STATUS=5** (dead) including retrieval of the variable **STATUSD** (date status=5) from **R09.SD2** is the simplest way of identifying all patients who died and dates of death during Phase 1.

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LIFE STATUS FORM FOR PATIENTS NOT SEEN FOR EXIT ANNUAL
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CONTENTS OF SAS DATASET: R92.SD2

DATA FROM CSSCD FORM 27 - LIFE STATUS FORM FOR PATIENTS NOT SEEN FOR EXIT ANNU
 VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
 IN THE SAS DATASET AND ON FORM 27

The SAS System 14:00 Wednesday, February 21, 2007 10

The CONTENTS Procedure

Data Set Name	OUT1.R92	Observations	1162
Member Type	DATA	Variables	9
Engine	V9	Indexes	0
Created	9:43 Tuesday, February 20, 2007	Observation Length	72
Last Modified	9:43 Tuesday, February 20, 2007	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	8192
Number of Data Set Pages	11
First Data Page	1
Max Obs per Page	113
Obs in First Data Page	82
Number of Data Set Repairs	0
File Name	r92.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
4	F92ALV30	Num	8	WAS PATIENT ALIVE WITHIN LAST 30 DAYS
2	F92CYCLE	Num	8	RECORD 92 CYCLE
9	F92PALIV	Num	8	APPROX. DATE PATIENT KNOWN ALIVE - RECODE DAYS SINCE DOE
8	F92PMOVE	Num	8	APPROX. DATE PATIENT MOVED - RECODE DAYS SINCE DOE
3	F92REAS	Num	8	REASON PATIENT NOT SEEN FOR EXIT ANNUAL
5	F92WHY	Num	8	REASON PATIENT WAS KNOWN TO BE ALIVE
6	JF92DTH1	Num	8	DATE PATIENT DIED - RECODE DAYS SINCE DOE
7	JF92DTH2	Num	8	DATE PATIENT DIED - RECODE DAYS SINCE DOE

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LIFE STATUS FORM FOR PATIENTS NOT SEEN FOR EXIT ANNUAL
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* R92.FMT contains value labels for numerical codes assigned to categorical*
* variables in the SAS dataset R92.SD2 *
*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 06/12/99 12:58:49;

PROC FORMAT;

* FORMAT F92REAS IS DEFINED FOR VARIABLE F92REAS;

VALUE F92REAS
1 = 'DIED'
2 = 'MOVED'
3 = 'LOST'
4 = 'REFUSING -HMO'
5 = 'REFUSING -OTHER'
6 = 'TRANSFERRED'
7 = 'CHRONIC CARE FAC.'
8 = 'UNABLE TO CONTACT'
9 = 'UNABLE TO SCHED.'
10 = 'OTHER';

* FORMAT F92ALVF IS DEFINED FOR VARIABLE F92ALV30;

VALUE F92ALVF
1 = 'NO'
2 = 'YES'
3 = 'UNKNOWN';

* FORMAT F92WHY IS DEFINED FOR VARIABLE F92WHY;

VALUE F92WHY
1 = 'SAW IN HOSP.'
2 = 'OUTSIDE CONTACT'
3 = 'PHONE'
4 = 'RELATIVE SAID SO'
5 = 'FRIEND SAID SO'
6 = 'OTHER';

* FORMAT
F92REAS F92REAS.
F92ALV30 F92ALVF.
F92WHY F92WHY.;

RUN;
QUIT;

CODEBOOK FOR CSSCD FORM 27
 LIFE STATUS FORM FOR PATIENTS NOT SEEN FOR EXIT ANNUAL - PAGE 1
 CSSCD FULL COHORT PATIENTS

F92CYCLE ----- RECORD 92 CYCLE
 type: numeric (float)

range: [1,2] units: 1
 unique values: 2 coded missing: 0 / 1162

tabulation:	Freq.	Value
	1159	1
	3	2

F92VDATE ----- VERSION DATE **DELETED**

type: numeric daily date (int)
 label: datelab

range: [9678,9678] units: 1
 or equivalently: [01jul1986,01jul1986] units: days
 unique values: 1 coded missing: 0 / 1162

tabulation:	Freq.	Numeric	Label
	1162	9678	07/01/86

F92REAS ----- REASON PATIENT NOT SEEN FOR EXIT ANNUAL

type: numeric (float)
 label: F92REAS

range: [1,10] units: 1
 unique values: 10 coded missing: 0 / 1162

tabulation:	Freq.	Numeric	Label
	31	1	DIED
	192	2	MOVED
	337	3	LOST
	43	4	REFUSING -HMO
	231	5	REFUSING -OTHER
	39	6	TRANSFERRED
	6	7	CHRONIC CARE FAC.
	82	8	UNABLE TO CONTACT
	106	9	UNABLE TO SCHED.
	95	10	OTHER

CODEBOOK FOR CSSCD FORM 27
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CSSCD FULL COHORT PATIENTS

F92MVEMO ----- MONTH PATIENT MOVED **DELETED**

type: numeric (float)

range: [1,12]

units: 1

unique values: 12

coded missing: 1003 / 1162

tabulation:	Freq.	Value
	12	1
	6	2
	16	3
	15	4
	4	5
	21	6
	18	7
	16	8
	14	9
	12	10
	10	11
	15	12

F92MVEMO:

1. Required only if F92REAS=2.

F92MVEYR ----- YEAR PATIENT MOVED **DELETED**

type: numeric (float)

range: [79,87]

units: 1

unique values: 9

coded missing: 982 / 1162

tabulation:	Freq.	Value
	7	79
	16	80
	29	81
	30	82
	24	83
	15	84
	31	85
	20	86
	8	87

F92MVEYR:

1. Required only if F92REAS=2.

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LIFE STATUS FORM FOR PATIENTS NOT SEEN FOR EXIT ANNUAL - PAGE 1
 CSSCD FULL COHORT PATIENTS

F92STATE ----- LAST KNOWN STATE OF RESIDENCE **DELETED**

type: numeric (float)

range: [5,999]

units: 1

unique values: 33

coded missing: 975 / 1162

tabulation:

Freq.	Value
6	5
5	11
2	17
20	52
2	71
15	80
4	141
7	156
3	160
1	180
6	219
1	284
3	286
8	312
8	315
6	320
2	330
10	340
2	346
25	362
3	371
3	390
7	470
5	507
13	517
10	546
2	572
2	580
1	802
1	803
2	805
1	820
1	999

F92STATE:

1. Required only if F92REAS=2.
2. See Appendix B - STATE AND COUNTRY CODE LIST.

10.0: Other - Overview

F92ALV30 ----- WAS PATIENT ALIVE WITHIN LAST 30 DAYS

type: numeric (float)

label: F92ALV30

range: [1,3] units: 1
unique values: 3 coded missing: 7 / 1162

tabulation:	Freq.	Numeric	Label
	30	1	NO
	348	2	YES
	777	3	UNKNOWN

F92LSTMO ----- MONTH PATIENT LAST KNOWN TO BE ALIVE **DELETED**

type: numeric (float)

range: [1,12] units: 1
unique values: 12 coded missing: 436 / 1162

tabulation:	Freq.	Value
	68	1
	52	2
	60	3
	67	4
	54	5
	89	6
	72	7
	70	8
	52	9
	53	10
	43	11
	46	12

F92LSTMO:

1. Required only if F92ALV30=3.

F92LSTYR ----- YEAR PATIENT LAST KNOWN TO BE ALIVE **DELETED**

type: numeric (float)

10.0: Other - Overview

range: [79,88] units: 1
unique values: 10 coded missing: 428 / 1162

tabulation:	Freq.	Value
	21	79
	58	80
	79	81
	84	82
	84	83
	111	84
	107	85
	121	86
	63	87
	6	88

F92LSTYR:

1. Required only if F92ALV30=3.

F92WHY ----- REASON PATIENT WAS KNOWN TO BE ALIVE

type: numeric (float)
label: F92WHY

range: [1,6] units: 1
unique values: 6 coded missing: 56 / 1162

tabulation:	Freq.	Numeric	Label
	549	1	SAW IN HOSP.
	82	2	OUTSIDE CONTACT
	274	3	PHONE
	52	4	RELATIVE SAID SO
	30	5	FRIEND SAID SO
	119	6	OTHER

F92WHY:

1. Required only if F92ALV30 not equal to 1.

_dta:

1. Created 07/28/00.

1	602.8
1	611.72
2	614.9
1	616.1

F200THN3:

1. Required only if F200THER=2
2. See ICD-9-CM codebook for diagnosis codes

_dta: