CONTENTS OF SAS DATASET: R75.SD2 DATA FROM CSSCD FORMS 12, 20, 22, 75 - CHEST AND SHOULDER X-RAY REPORT VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION IN THE SAS DATASET AND ON THE FORMS The SAS System 10:22 Tuesday, October 31, 2006

The CONTENTS Procedure

Data Set Name	OUT1.R75	Observations	5483
Member Type	DATA	Variables	16
Engine	V9	Indexes	0
Created	15:55 Tuesday, October 24, 2006	Observation Length	128
Last Modified	15:55 Tuesday, October 24, 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	12288
Number of Data Set Pages	58
First Data Page	1
Max Obs per Page	95
Obs in First Data Page	73
Number of Data Set Repairs	0
File Name	r75.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Туре	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
6	AVNCR	Num	8	AVASCULAR NECROSIS SHOULDER
5	BNABN	Num	8	BONE ABNORMALITIES
2	CARD	Num	8	CARDIOMEGALY
12	CTR	Num	8	C-T RATIO
9	CYSL	Num	8	SHOULDER CYSTIC LESIONS
14	F75FORM	Num	8	FORM ON WHICH DATA WAS SENT IN
13	F75RPT	Num	8	X-RAY REPORT RECEIVED
11	FMDEF	Num	8	FISH-MOUTH DEFORMITY
10	GNOST	Num	8	GENERALIZED OSTEOPOROSIS
15	JCHXR	Num	8	DATE CHEST X-RAY - RECODE DAYS SINCE DOE
16	JSXRAYDT	Num	8	DATE OF SHOULDER X-RAY - RECODE DAYS SINCE DOE
3	LNGIN	Num	8	LUNG INFILTRATE
4	PLEFF	Num	8	PLEURAL EFFUSION
8	SCLR	Num	8	SHOULDER SCLEROSIS
7	SHPROS	Num	8	SHOULDER PROSTHESIS

* * * * * * * R75.FMT contains value labels for numerical codes assigned to cagegorical * * variables in the SAS dataset R75.SD2 ****; * SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 07/01/99 14:12:31; PROC FORMAT; * FORMAT QUEST is used for the following variables: CARD BNABN AVNCR SCLR CYSL GNOST FMDEF; VALUE QUEST = 'YES' 1 2 = 'NO' 3 = '??'; * FORMAT T4X IS DEFINED FOR VARIABLE LNGIN; VALUE T4X 1 = 'LT-UPPER LOBE' 2 = 'LT-LINGULA' = 'LT-LOWER LOBE' 4 8 = 'RT-UPPER LOBE' 16 = 'RT-MIDDLE LOBE' 32 = 'RT-LOWER LOBE' 64 = 'NO' 0 = 'YES, SITE MISSING'; * FORMAT T5X IS DEFINED FOR VARIABLE PLEFF; VALUE T5X = 'RIGHT' 1 2 = 'LEFT' 3 = 'BOTH' = 'NO' 4 0 = 'YES,SITE MISSING'; * FORMAT T8X IS DEFINED FOR VARIABLE SHPROS; VALUE T8X = 'RIGHT' 1 = 'LEFT' 2 3 = 'BOTH'

4 = 'NO'; * FORMAT T13X IS DEFINED FOR VARIABLE F75RPT; VALUE T13X = 'YES' 1 2 = 'NO'; * FORMAT T14X IS DEFINED FOR VARIABLE F75FORM; VALUE T14X 12 = '12-INTAKE LAB' = '20-SECOND ANNUAL' 20 22 = '22-THIRD ANNUAL' 75 = '75-X-RAY FORM'; * FORMAT T2X. CARD BNABN AVNCR SCLR CYSL GNOST FMDEF QUEST. LNGIN T4X. PLEFF T5X. SHPROS T8X. F75RPT T13X. F75FORM T14X.; RUN; QUIT; F75VDATE ------ VERSION DATE DELETED type: numeric (float) label: datelab range: [7662,8629] units: 1 unique values: 2 coded missing: 5453 / 5483 tabulation: Freq. Numeric Label 21 7662 12/23/80 9 8629 08/17/83 CARD ----- CARDIOMEGALY type: numeric (float) label: CARD range: [1,2] units: 1 unique values: 2 coded missing: 1248 / 5483 tabulation: Freq. Numeric Label 2056 1 YES 2179 2 NO

LNGIN ------ LUNG INFILTRATE type: numeric (float) label: LNGIN range: [0,64] units: 1 C1 coded missing: 1194 / 5483 unique values: 24 tabulation: Freq. Numeric Label 0 YES,SITE MISSING(0) 16 1 LT-UPPER LOBE(1) 7 2 LT-LINGULA(2) 7 19 4 LT-LOWER LOBE(4) 1 5 1 6 1 7
 18
 8
 RT-UPPER LOBE(8)

 3
 9
 1 12 12 16 RT-MIDDLE LOBE(16) 2 19 1 27 32 RT-LOWER LOBE(32) 33 36 34

CHEST, SI		-	X-RAY REPORT FORM - PAGE 1
		CSSCD FUL	L COHORT PATIENTS
	2	38	
	- 1	40	
	1	44	
	3	48	
	1	52	
	2	54	
	1	62	
	11	63	
	4111	64	NO(64)
LNGIN:			
 Binary coded varia variables. 	ble. See	Part II	for explanation of binary coded
PLEFF			PLEURAL EFFUSION
	numeric	(float)	
label:		. ,	
range:			units: 1
unique values:	5		coded missing: 1196 / 5483
			1.1.3
tabulation:		Numeric	
	3 24		YES,SITE MISSING RIGHT
	24 14		LEFT
	14	2	
	4236	4	
	7200	-	

CODEBOOK FOR CSSCD FORM 75

BNABN ----- BONE ABNORMALITIES type: numeric (float) label: BNABN range: [1,2] units: 1 unique values: 2 coded missing: 2763 / 5483 tabulation: Freq. Numeric Label 417 1 YES 2303 2 NO AVNCR ------ AVASCULAR NECROSIS SHOULDER type: numeric (float) label: AVNCR range: [1,3] units: 1 unique values: 3 coded missing: 473 / 5483 tabulation: Freq. Numeric Label
 335
 1
 YES

 4658
 2
 NO

 17
 3
 ??
 SHPROS ------ SHOULDER PROSTHESIS type: numeric (float) label: SHPROS range: [1,4] units: 1 unique values: 2 coded missing: 4573 / 5483 tabulation: Freq. Numeric Label 2 1 RIGHT 908 4 NO SCLR ------ SHOULDER SCLEROSIS type: numeric (float) label: SCLR range: [1,2] units: 1 values: 2 coded missing: 603 / 5483 unique values: 2 tabulation: Freq. Numeric Label 486 1 YES 4394 2 NO

CYSL ------ SHOULDER CYSTIC LESIONS type: numeric (float) label: CYSL range: [1,2] units: 1 coded missing: 644 / 5483 unique values: 2 tabulation: Freq. Numeric Label 100 1 YES 4739 2 NO GNOST ----- GENERALIZED OSTEOPOROSIS type: numeric (float) label: GNOST range:[1,2]units:1values:2coded missing:2820 / 5483 unique values: 2 tabulation: Freq. Numeric Label 285 1 YES 2378 2 NO FMDEF ------ FISH-MOUTH DEFORMITY type: numeric (float) label: FMDEF range: [1,2] units. . values: 2 coded missing: 2832 / 5483 unique values: 2 tabulation: Freq. Numeric Label 1 YES 385 2266 2 NO CTR ----- C-T RATIO type: numeric (float) range: [.3,.81] units: .01 /alues: 43 coded missing: 4177 / 5483 unique values: 43 mean: .523714 std. dev: .062729 10% 25% 50% 75% .45 .49 .52 .56 percentiles: 75% 90% .6

F75RPT ----- X-RAY REPORT RECEIVED type: numeric (float) label: F75RPT range: [1,2] units: 1 unique values: 2 coded missing: 3568 / 5483 tabulation: Freq. Numeric Label 1 YES 1256 659 2 NO F75FORM ----- FORM ON WHICH DATA WAS SENT IN type: numeric (float) label: F75FORM range: [12,75] units: 1 unique values: 4 coded missing: 0 / 5483 tabulation: Freq. Numeric Label 12 12-INTAKE LAB 2927 110 20 20-SECOND ANNUAL 22 22-THIRD ANNUAL 1510 75 75-X-RAY FORM 936

dta:

1. Created 08/01/00.

- A. <u>List of variables deleted</u> CHXR F75INIT F75NDATE F75LASTU F75LASTE F75ESTAT F75VDATE F75FCB SXRAYDT
- B. List of variables modified NONE
- C. List of variables modified with a name change NONE
- D. <u>Old name</u>
- E. <u>New name</u>
- F. List of variables modified date to days since DOE
- G. Old name CHXR SXRAYDT
- H. <u>New name</u> **JCHXR JSXRAYDT**
- I. <u>Collection Information</u>:

Form 75 (Chest, Shoulder, Hip X-Ray Report Form) was to be filled out whenever a study chest x-ray, shoulder x-ray, or hip and pelvis x-ray (see Section

6.4) was completed. Chest and shoulder x-rays were required at entry or age 1 at the earliest. They were required at the second annual visit only if not done at entry. During the extension, shoulder x-rays were to be repeated on patients \geq 10 years of age if the last x-ray was done more than 4 years ago. During the exit period which began in May of 1986, repeat x-rays were required only for the small number of "control" patients whose earlier films were centrally reviewed at the University of Tennessee Health Sciences Center (See variable **SHOULDER** in Section 1.0 (SAS dataset: **R09.SD2**). However, if any of these patients had repeat x-rays done after August 1983, another study was not required. Repeat x-rays for all "controls" were also sent to the University of Tennessee Health Sciences Center (See Variable Sciences Center for central reading.

- J. Data Collection Period: 03/79-09/88
- K. Form Version Dates: 12/23/80, 08/17/83
- <u>Files Used to Store Information</u>: SAS System Files: **R75.SD2** Format Files: **R75.FMT**
- M. Unique Record Identifiers: ANONID, CHXR

Records within the dataset are sorted by **ANONID** and **CHXR** (see H below).

N. Number of Observations (Patients) in SAS Dataset: 5483 (3142)

The number of shoulder x-rays completed for each patient is summarized below:

# of	# of
x-rays	patients
0	99
1	1176
2	1683
3	179
4	5

O. <u>Contents of SAS Dataset</u>:

- Alphabetical Listing of Variables: See p. 1
- Listing of Variables by Position: See p. 2

P. Notes About Selected Variables:

- CHXR is the variable name for date of chest x-ray and was used as a sort ID variable within the dataset. If only shoulder x-rays were done, the date of the shoulder x-ray was entered as the chest x-ray date.
- Q. Computed Variables: None

R. Inter-Relationship With Other Datasets:

Other sources of information relevant to shoulder x-ray findings or aseptic necrosis are

Phase 1 Forms	SAS Dataset	See Section
Chest, Shoulder, Hip X-ray Report Form	R76.SD2	6.4
Aseptic Necrosis	R64.SD2	8.2.1
Aseptic Necrosis Central Review Results	R65.SD2	8.2.2
"Roster"	R09.SD2	1.0 (variables: SHOULDER, HIP, ANDATE,
		VARDATE)
Past Medical History	R10.SD2	2.3
Surgery and Anesthesia	R83.SD2	9.1

S. List of variables deleted HIPDT F76INIT F76NDATE F76LASTU F76LASTE

F76ESTAT F76VDATE F76FCB

- T. List of variables modified NONE
- U. List of variables modified with a name change NONE
- V. <u>Old name</u>
- W. <u>New name</u>
- X. List of variables modified date to days since DOE
- Y. <u>Old name</u> **HIPDT**
- Z. <u>New name</u> **JHIPDT**
- AA.Collection Information:

Form 75 (Chest, Shoulder, Hip X-Ray Report Form) was to be filled out

whenever a study chest x-ray, shoulder x-ray, or hip and pelvis x-ray was completed.

Hip and pelvis x-rays were required at entry for patients entered at age \geq 5 years and at age 5 for patients entered at age < 5 years. Repeat studies were required for patients \geq 10 years of age during the extension if the last study was completed more than 4 years ago. During the exit period which began in May of 1986, repeat x-rays were required only for the small number of "control" patients whose earlier films were centrally reviewed at the University of Tennessee Health Sciences Center (See variable **HIP** in Section 1.0 (SAS dataset: **R09.SD2**). However, if any of these patients had repeat x-rays done after August 1983, another study was not required. Repeat x-rays for all "controls" were also sent to the University of Tennessee Health Sciences Center for central reading.

BB.<u>Data Collection Period</u>: 03/79 – 09/88

- CC. Form Version Dates: 08/17/83
- DD. <u>Files Used to Store Information</u>: SAS System Files: **R76.SD2** Format Files: **R76.FMT**

EE. Unique Record Identifiers: ANONID, HIPDT

Records within the dataset are sorted by ANONID and HIPDT

FF. Number of Observations (Patients) in SAS Dataset: 4869 (2879)

The number of hip x-rays completed for each patient is summarized below:

# of	# of
x-rays	patients
1	1049
2	1677
3	147
4	5
5	1

GG. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See p. 1
- Listing of Variables by Position: See p. 2
- HH. Notes About Selected Variables: None
- II. Computed Variables: None

JJ. Inter-Relationship With Other Datasets:

Other sources of information relevant to hip and pelvis x-ray findings or aseptic

necrosis are

Phase 1 Forms Chest, Shoulder, Hip X-ray Report Form	SAS Dataset R75.SD2	See Section 6.3
Aseptic Necrosis	R64.SD2	8.2.1
Aseptic Necrosis Central Review Results	R65.SD2	8.2.2
"Roster"	R09.SD2	1.0 (variables: SHOULDER, HIP, ANDATE, VARDATE)
Past Medical History Surgery and Anesthesia	R10.SD2 R83.SD2	2.3 9.1
Ourgery and Anesthesia	N03.0DZ	5.1

CONTENTS OF SAS DATASET: R76.SD2 DATA FROM CSSCD FORMS 12, 22, 75 - HIP X-RAY REPORT VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION IN THE SAS DATASET AND ON THE FORMS The SAS System 10:22 Tuesday, October 31, 2006 4

The CONTENTS Procedure

Data Set Name	OUT1.R76	Observations	4869
Member Type	DATA	Variables	7
Engine	V9	Indexes	0
Created	16:02 Tuesday, October 24, 2006	Observation Length	56
Last Modified	16:02 Tuesday, October 24, 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	8192
Number of Data Set Pages	34
First Data Page	1
Max Obs per Page	145
Obs in First Data Page	112
Number of Data Set Repairs	0
File Name	r76.sas7bdat
Release Created	9.0000M0
Host Created	XP_PR0

Alphabetic List of Variables and Attributes

Variable Type Len Label

CODEBOOK FOR CSSCD FORM 75 CHEST, SHOULDER, HIP X-RAY REPORT FORM

CSSCD FULL COHORT PATIENTS

1	ANONID	Char	8	ANONYMIZED ID #
6	F76FORM	Num	8	FORM ON WHICH DATA WAS SENT IN
5	F76RPT	Num	8	X-RAY REPORT RECEIVED
2	HPF	Num	8	HIP AND PELVIS FILMS
3	HPFAN	Num	8	ASEPTIC NECROSIS HIP
4	HPPROS	Num	8	HIP PROSTHESIS
7	JHIPDT	Num	8	DATE OF HIP-PELVIS X-RAYS - RECODE DAYS SINCE DOE

**** * R76.FMT contains value labels for numerical codes assigned to categorical* * variables in the SAS dataset R76.SD2 ****; * SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 06/12/99 12:48:17; PROC FORMAT; VALUE HPF 1 = 'NORMAL' 2 = 'ABNORMAL' 3 = '??'; VALUE HPFAN 1 = 'YES' = 'NO' 2 = '??'; 3 VALUE HPPROS 1 = 'RIGHT' 2 = 'LEFT' = 'BOTH' 3 = 'NO'; 4 VALUE F76RPT 1 = 'YES'

SECTION 6.4 CHEST, SHOULDER, HIP X-RAY REPORT FORM FORM 75

2 = 'NO';

VALUE F76FORM 12 = '12-INTAKE LAB'

22	=	'22-THIRD	ANNUAL '
75	=	'75-X-RAY	FORM';

* FORMAT

HPF HPF. HPFAN HPFAN. HPPROS HPPROS. F76RPT F76RPT. F76FORM F76FORM.;

RUN;

QUIT;

CODEBOOK FOR CSSCD "RECORD" 26

SPLEEN SCAN TEST FOR PATIENTS < 2 YEARS OF AGE

CSSCD FULL COHORT PATIENTS

F76VDATE					····· VERSION DATE	DELETED
type:	numeric	daily da	te (int)			
label:	datelab					
range:	[8629.8	629]		units:	1	
or equivalently:						
unique values:		000,17449			4860 / 4869	
unique values.	I		coueu	missing.	4000 / 4009	
tobulation.	F n n n	Numerale	l ahal			
tabulation:	-					
	9	8629	08/17/83			
HPF				HI	P AND PELVIS FILMS	
type:	numeric	(float)				
label:						
range:	[1.3]			units:	1	
unique values:			coded		84 / 4869	
unique values.	5		coueu	missing.	04 / 4009	
+ + h - 1 - +	Free	Noncoda	1			
tabulation:	-	NUMERIC	Label			
	3863		NORMAL			
	907		ABNORMAL			
	15	3	??			
HPFAN				AS	SEPTIC NECROSIS HIP	
type:	numeric	(float)				
label:		. ,				
range:	[1 3]			units:	1	
unique values:			oodod		, 783 / 4869	
unique varues.	3		coueu	missing.	/03 / 4009	
	_					
tabulation:	•					
	482	-				
	3575	2	NO			
	29	3	??			
HPPROS					HIP PROSTHESIS	
type:		(float)				
label:	HPPROS	()				
Tabel.						
	[4] 41				4	
range:	[1,4]			units:		
unique values:	4		coded	missing:	3914 / 4869	
tabulation:	Freq.	Numeric	Label			
	7	1	RIGHT			
	20	2	LEFT			
	13	3				
	915	4				
		-				

CODEBOOK FOR CSSCD "RECORD" 26

SPLEEN SCAN TEST FOR PATIENTS < 2 YEARS OF AGE

CSSCD FULL COHORT PATIENTS

F76RPT			X-RAY REPORT RECEIVED
type:	numeric	(float)	
label:	F76RPT	. ,	
range:	[1,2]		units: 1
unique values:	2		coded missing: 2884 / 4869
tabulation:	Freq.	Numeric	Label
	1293	1	YES
	692	2	NO
F76FORM			FORM ON WHICH DATA WAS SENT IN
type:	numeric	(float)	
••	F76FORM	. ,	
140011			
range:	[12,75]		units: 1
unique values:	3		coded missing: 0 / 4869
	•		
tabulation:	Freq.	Numeric	Label
	2475	12	12-INTAKE LAB
	1455	22	22-THIRD ANNUAL
	939		75-X-RAY FORM
	333	75	

_dta:

KK. <u>List of variables deleted</u> F26LASTU F26LASTE F26ESTAT F26DATE F26BEFDT F26AFTDT F26BPITD F26RFUNC F26RSIZE

LL. List of variables modified NONE

MM. List of variables modified with a name change NONE

- NN. Old name
- OO. <u>New name</u>
- PP. List of variables modified date to days since DOE

QQ. Old name F26DATE F26BEFDT F26AFTDT F26BPITD

RR. <u>New name</u> JF26DATE J26BEFDT J26AFTDT J26BPITD

SS.Collection Information:

A spleen scan was to be performed at 9 months of age on HbSS infants. The scan was to be done earlier if HbF was < 20%, Howell-Jolly bodies were present, pocked RBC count was > 3.5%, or patient had a severe bacterial infection. Spleen scans were required for SC patients only if Howell Jolly bodies were present, pocked

^{1.} Created 08/01/00.

CODEBOOK FOR CSSCD "RECORD" 26 SPLEEN SCAN TEST FOR PATIENTS < 2 YEARS OF AGE CSSCD FULL COHORT PATIENTS

RBC count was > 3.5%, or there was a severe bacterial infection. Blood to be sent to Yale for pocked RBC count was to be drawn on the same day the spleen scan was done.

TT. Data Collection Period: 03/79 – 10/82

UU. Form Version Dates: N/A

VV.Files Used to Store Information: SAS System Files: R26.SD2 Format Files: R26.FMT

WW. Unique Record Identifiers: ANONID, F26CYCLE Records within the dataset are sorted by **ANONID** and **F26CYCLE**

XX.Number of Observations (Patients) in SAS Dataset: 91 (91)

YY.Contents of SAS Dataset:

- Alphabetical Listing of Variables: See p. 1 •
- Listing of Variables by Position: See p. 2 •
- ZZ. Notes About Selected Variables: None

AAA. Computed Variables:

- F26BEFDT, F26AFTDT are variable names for closest routine visit dates preceding and following the spleen scan respectively. These variables were updated using date information from routine visit forms 16, 12, or 17 (See Section 4).
- **F26BPITD**, **F26APITD** are variable names for closest pocked RBC count dates • preceding and following the spleen scan respectively. These variables were updated using date information from pocked RBC records (See section 5.2)
- F25BEFC, F26AFTC are variable names for closest routine visit cycles • preceding and following the spleen scan respectively. These variables were updated using the cycle values for the closest routine visits preceding and following the scan (See Section 4).

BBB. Inter-Relationship With Other Datasets:

CSSCD FULL COHORT PATIENTS

Other sources of information relevant to splenic function, splenic sequestration,

and splenectomy are

Phase 1 Forms	SAS Dataset	See Section
Pit Count Report Form	R07.SD2	5.2
Form 16	R16.SD2	4.1
Form 16E	R24.SD2	4.2
Form 11	R1121.SD2	4.3
Form 12	R1222.SD2	4.4
Forms 17, 19, 20, 21, 24	R1722.SD2	4.5
Form 25	R25.SD2	4.6
Form 46	R46.SD2	7.6.1
Form 48	R48.SD2	7.7.1
	R58.SD2	7.7.3
Form 53	R53.SD2	7.9
Form 83	R83.SD2	9.1
Form 10	R10.SD2	2.3
Form 15	R15.SD2	2.2
"Roster"	R09.SD2	1.0 (variable: SPLNSTAT)

CONTENTS OF SAS DATASET: R26.SD2

DATA FROM CSSCD "RECORD" 26 - SPLEEN SCAN REPORT FOR PATIENTS < 2 YEARS OF AGE VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION IN THE SAS DATASET

The SAS System

10:22 Tuesday, October 31, 2006 5

The CONTENTS Procedure

Data Set Name	OUT1.R26	Observations	91
Member Type	DATA	Variables	11
Engine	V9	Indexes	0
Created	16:21 Tuesday, October 24, 2006	Observation Length	88
Last Modified	16:21 Tuesday, October 24, 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	8192
Number of Data Set Pages	2
First Data Page	1
Max Obs per Page	92
Obs in First Data Page	64
Number of Data Set Repairs	0
File Name	r26.sas7bdat
Release Created	9.0000M0
Host Created	XP_PR0

CSSCD FULL COHORT PATIENTS

Alphabetic List of Variables and Attributes

#	Variable	Туре	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
6	F26AFTC	Num	8	CLOSEST CYCLE FOLLOWING SCAN
7	F26APITD	Num	8	CLOSEST PIT DATE FOLLOWING SCAN
5	F26BEFC	Num	8	CLOSEST CYCLE PRECEEDING SCAN
2	F26CYCLE	Num	8	CYCLE NUMBER
3	F26IFUNC	Num	8	SPLEEN FUNCTION-INSTITUTIONAL
4	F26ISIZE	Num	8	SPLEEN SIZE-INSTITUTIONAL
10	J26AFTDT	Num	8	CLOSEST DATE OF ROUTINE VISIT FOLLOWING - RECODE DAYS
SINCE	DOE			
9	J26BEFDT	Num	8	CLOSEST DATE OF ROUTINE VISIT PRECEEDING - RECODE DAYS
SINCE	DOE			
11	J26BPITD	Num	8	CLOSEST PIT DATE PRECEEDING SCAN - RECODE DAYS SINCE
DOE				
8	JF26DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 06/11/99 14:42:33;

PROC FORMAT;

*FORMAT FUNC used for the following variables: F26IFUNC;

VALUE FUNC

1	= 'NORMAL'
2	= 'HYPOSPLENIA'
3	= 'ASPLENIA'
4	= 'HYPERSPLENIA';

*FORMAT ENLG used for the following variables: F26ISIZE F26ILIVS F26RLIVS;

CODEBOOK FOR CSSCD "RECORD" 26 SPLEEN SCAN TEST FOR PATIENTS < 2 YEARS OF AGE

CSSCD FULL COHORT PATIENTS

VALUE ENLG

0	=	'NOT ENLARGED'
1	=	'ENLARGED'
9	=	'MISSING';

*FORMAT NDAI used for the following variables: F26ILIVF F26RLIVF;

VALUE NDAI

1	= 'NORMAL'
2	= 'DECREASED'
3	= 'ABSEND'
4	= 'INCREASED';

* FORMAT F26IFUNC FUNC. F26ISIZE F26ILIVS F26RLIVS ENLG. F26ILIVF F26RLIVF NDAI.;

RUN; QUIT;

SPLEEN SCAN TEST FOR PATIENTS < 2 YEARS OF AGE

CSSCD FULL COHORT PATIENTS

F26CYCLE CYCLE NUMBER type: numeric (float) range: [1,1] units: 1 coded missing: 0 / 91 unique values: 1 tabulation: Freq. Value 91 1 F26IFUNC ------ SPLEEN FUNCTION-INSTITUTIONAL type: numeric (float) label: F26IFUNC range: [1,4] unico. /alues: 4 coded missing: 0 / 91 unique values: 4 tabulation: Freq. Numeric Label 1 NORMAL 53 15 2 HYPOSPLENIA 3 ASPLENIA 22 1 4 HYPERSPLENIA type: numeric (float) label: F26ISIZE
 range:
 [0,1]
 units:
 1

 unique values:
 2
 coded missing:
 0 / 91
 tabulation: Freq. Numeric Label 72 0 NOT ENLARGED 19 1 ENLARGED F26BEFC ------ CLOSEST CYCLE PRECEEDING SCAN type: numeric (float) range: [4,26] units: 1 coded missing: 1 / 91 unique values: 15 2 14 tabulation: Freq. Value 2 16 2 20 24 1 5 2 21 6 6 1 26 1 7 8 8 30 9 15 10 4 11 tabulation: Freq. Value 11 12 3 13

SECTION 6.5 SPLEEN SCAN "RECORD" 26

F26AFTC ------ CLOSEST CYCLE FOLLOWING SCAN type: numeric (float) range: [8,18] units: 1 coded missing: 64 / 91 unique values: 8 tabulation: Freq. Value 38 39 1 11 10 12 4 13 2 15 1 16 3 18 DELETED type: numeric (float) label: F26RFUNC range: [1,3] /alues: 3 units: 1 unique values: 3 coded missing: 61 / 91 tabulation: Freq. Numeric Label 12 1 NORMAL 8 2 HYPOSPLENIA 10 3 ASPLENIA F26RSIZE ------ SPLEEN SIZE-REVIEWER DELETED type: numeric (float) label: F26RSIZE range: [0,1] units: 1 unique values: 2 coded missing: 62 / 91 tabulation: Freq. Numeric Label 0 NOT ENLARGED 27 2 1 ENLARGED dta: 1. Created 8/9/2000. CCC. List of variables deleted XRD F77INIT F77NDATE F77LASTU F77LASTE F77ESTAT F77VDATE F77FCB DDD. List of variables modified NONE List of variables modified with a name change NONE EEE. FFF. Old name GGG. New name

SECTION 6.3 CHEST, SHOULDER< HIP X-RAY REPORT FORM

- HHH. List of variables modified date to days since DOE
- III. <u>Old name</u> **XRD**
- JJJ. <u>New name</u> JXRD
- KKK. <u>Collection Information</u>:

Form 77 (**Plain Film Report Form**) was to be filled out whenever a study abdominal x-ray was completed. Plain films of the abdomen were required for patients entered at 10-14 years of age and at 25-30 years of age. This x-ray was also required for patients entered at < 10 years of age who turned 10 before August 1983 and for patients entered at < 25 years of age who turned 25 before August 1983. If gallstones were absent on plain film (or results were equivocal), an oral cholecystogram or sonogram was to be done on patients in the older age range. In 1983, it was decided that oral cholecystograms were acceptable only if they showed gallstones. If an oral cholecystogram was done and showed no stones, a sonogram was required. A plain film was not required for a patient who had a cholecystectomy prior to entry (or entry into the age range for which the x-ray was required). In a few cases, results obtained at the time of a right upper quadrant (RUQ) event were used to meet this requirement.

- LLL. Data Collection Period: 03/79 10/85
- MMM. Form Version Dates: 02/02/84
- NNN. <u>Files Used to Store Information</u>:
 SAS System Files: **R77.SD2** Format Files: **R77.FMT**
- OOO. <u>Unique Record Identifiers</u>: **ANONID**, **XRD** Records within the dataset are sorted by **ANONID** and **XRD**
- PPP. Number of Observations (Patients) in SAS Dataset: 1640 (1566)

Seventy-three of the 1566 patients had a repeat abdominal x-ray during the study period.

- QQQ. Contents of SAS Dataset:
 - Alphabetical Listing of Variables: See p. 1
 - Listing of Variables by Position: See p. 2

RRR. Notes About Selected Variables: None

SSS. Computed Variables: None

TTT. Inter-Relationship With Other Datasets:

Other sources of information relevant to gallstone data are

Phase 1 Forms	SAS Dataset	See Section
"Roster"	R09.SD2	1.0 (variables: PFLMSTAT , SONOGRAM)
78	R78.SD2	6.6.2
79	R79.SD2	6.6.3
10	R10.SD2	2.3
17, 19, 20, 21, 24	R1722.SD2	4.5
25	R25.SD2	4.6
34	R34.SD2	7.3.1
83	R83.SD2	9.1

CONTENTS OF SAS DATASET: R77.SD2 DATA FROM CSSCD FORM 77 - PLAIN FILM REPORT FORM VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION IN THE SAS DATASET AND ON FORM 77 The SAS System 10:22 Tuesday, October 31, 2006 6

The CONTENTS Procedure

Data Set Name	OUT1.R77	Observations 164	0
Member Type	DATA	Variables 8	
Engine	V9	Indexes 0	
Created	11:20 Wednesday, October 25, 2006	Observation Length 64	
Last Modified	11:20 Wednesday, October 25, 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	8192
Number of Data Set Pages	14
First Data Page	1
Max Obs per Page	127
Obs in First Data Page	97
Number of Data Set Repairs	0
File Name	r77.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Туре	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
7	F77FORM	Num	8	FORM ON WHICH DATA WAS SENT IN
6	F77RPT	Num	8	PFLM REPORT RECEIVED
8	JXRD	Num	8	DATE OF PLAIN FILM - RECODE DAYS SINCE DOE
2	XGAL	Num	8	GALLSTONES
3	XGFL	Num	8	GAS FILLED LOOPS
5	XPNC	Num	8	PANCREATIC CALCIFICATION
4	XPSOA	Num	8	PSOAS SHADOWS

**** * R77.FMT contains value labels for numerical codes assigned to categorical* * variables in the SAS dataset R77.SD2 * ****; PROC FORMAT; * SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 10/21/99 14:34:22; VALUE XGAL 1 = 'PRESENT' 2 = 'ABSENT' 3 = '??'; * FORMAT YES_NO is used for the following variables: XGFL F77RPT; VALUE YES_NO 1 = 'YES' 2 = 'NO'; VALUE XPSOA 1 = 'SEEN'

```
2 = 'NOT SEEN';
```

VALUE XPNC 1 = 'YES'

SECTION 6.3 CHEST, SHOULDER< HIP X-RAY REPORT FORM

2 = 'NO' 3 = '??';

* FORMAT MMDDYY8. XGAL XGAL. XGFL F77RPT YES_NO. XPSOA XPSOA. XPNC XPNC.;

RUN;

QUIT;

F77VDATE VERSION DATE DELETED type: numeric (int) range: [.,.] units: . /alues: 0 coded missing: 1640 / 1640 unique values: O tabulation: Freq. Value XGAL ------ GALLSTONES type: numeric (float) label: XGAL range:[1,3]units:1values:3coded missing:4 / 1640 unique values: 3 tabulation: Freq. Numeric Label 231 1 PRESENT 1392 2 ABSENT 13 3 ?? XGFL ----- GAS FILLED LOOPS type: numeric (float) label: XGFL range: [1,2] units: 1 unique values: 2 coded missing: 117 / 1640 tabulation: Freq. Numeric Label 1 YES 340 1183 2 NO XPSOA ----- PSOAS SHADOWS type: numeric (float) label: XPSOA

 range:
 [1,2]
 units:
 1

 values:
 2
 coded missing:
 151 / 1640

 unique values: 2 tabulation: Freq. Numeric Label 446 1 SEEN 1043 2 NOT SEEN XPNC ------ PANCREATIC CALCIFICATION type: numeric (float) label: XPNC units: 1 range: [1,2]units: 1unique values: 2coded missing: 100 / 1640 tabulation: Freq. Numeric Label 1 YES 2 NO 17 1523

SECTION 6.3 CHEST, SHOULDER< HIP X-RAY REPORT FORM

FORM	75
------	----

F77RPT ----- PFLM REPORT RECEIVED type: numeric (float) label: F77RPT range: [1,2] units: 1 unique values: 2 coded missing: 1441 / 1640 tabulation: Freq. Numeric Label 1 YES 167 2 NO 32 ----- FORM ON WHICH DATA WAS SENT IN F77FORM -----type: numeric (float) range: [12,77] units: 1 unique values: 2 coded missing: 0 / 1640 tabulation: Freq. Value 1609 12 31 77

```
dta:
```

1. Created 10/27/99

UUU. <u>List of variables deleted</u> SONODT F78INIT F78NDATE F78LASTU F78LASTE F78ESTAT F78VDATE F78FCB

- VVV. List of variables modified NONE
- WWW. List of variables modified with a name change NONE
- XXX. <u>Old name</u>
- YYY. <u>New name</u>
- ZZZ. List of variables modified date to days since DOE
- AAAA. <u>Old name</u> SONODT
- BBBB. <u>New name</u> **JSONODT**
- CCCC. Collection Information:

Form 78 (Sonogram Report Form) was to be filled out whenever a study sonogram was completed. This test was required for patients entered between 25-30 years of age or who turned 25 before August 1983 if a plain film of the abdomen was negative (or equivocal) for gallstones and an oral cholecystogram was either not done or negative for gallstones. Repeat sonograms were required for patients 4 years after the initial study sonogram if gallstones were not present on the initial sonogram. The repeat sonogram requirement was discontinued in May 1986. Sonograms were also required at exit for a random sample of $4 \propto$ gene HbSS patients between the ages of 10-12 years.

DDDD. Data Collection Period: 03/79 - 10/87

EEEE. Form Version Dates: 08/17/83

- FFFF. <u>Files Used to Store Information</u>: SAS System Files: **R78.SD2** Format Files: **R78.FMT**
- GGGG. <u>Unique Record Identifiers</u>: **ANONID**, **SONODT** Records within the dataset are sorted by **ANONID** and **SONODT**

HHHH. Number of Observations (Patients) in SAS Dataset: 601 (528)

Seventy-one of the 528 patients have two sonogram records on the database.

- IIII. Contents of SAS Dataset:
 - Alphabetical Listing of Variables: See p. 1
 - Listing of Variables by Position: See p. 2
- JJJJ. Notes About Selected Variables: None
- KKKK. Computed Variables: None

LLLL. Inter-Relationship With Other Datasets:

Other sources of information for gallstone data are

Phase 1 Forms	SAS Dataset	See Section
"Roster"	R09.SD2	1.0 (variables: PFLMSTAT , SONOGRAM)
77	R77.SD2	6.6.1
79	R79.SD2	6.6.3
10	R10.SD2	2.3
17, 19, 20, 21, 24	R1722.SD2	4.5
25	R25.SD2	4.6
34	R34.SD2	7.3.1
83	R83.SD2	9.1

CONTENTS OF SAS DATASET: R78.SD2 DATA FROM CSSCD FORM 78 - SONOGRAM REPORT FORM VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION IN THE SAS DATASET AND ON FORM 78 The SAS System 10:22 Tuesday, October 31, 2006 7

The CONTENTS Procedure

Data Set Name	OUT1.R78	Observations	601
Member Type	DATA	Variables	5
Engine	V9	Indexes	0
Created	11:24 Wednesday, October 25, 2006	Observation Length	40
Last Modified	11:24 Wednesday, October 25, 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	4096
Number of Data Set Pages	7
First Data Page	1
Max Obs per Page	101
Obs in First Data Page	61
Number of Data Set Repairs	0
File Name	r78.sas7bdat
Release Created	9.0000M0
Host Created	XP_PR0

Alphabetic List of Variables and Attributes

#	Variable	Туре	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
4	F78FORM	Num	8	FORM ON WHICH DATA WAS SENT IN
3	F78RPT	Num	8	SONOGRAM REPORT RECEIVED

SECTION 6.3 CHEST, SHOULDER< HIP X-RAY REPORT FORM

FORM	75

```
JSONODT
                       DATE OF SONOGRAM - RECODE DAYS SINCE DOE
   2
      SONO
              Num
                    8
                       SONOGRAM RESULTS
*****
* R78.fmt contains value labels for numerical codes assigned to
categorical *
* variables in the SAS dataset R78.SD2
****;
* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 10/28/99 14:36:45;
PROC FORMAT;
   VALUE SONO
               = 'ABNORMAL ?'
   1
   2
               = 'GALLSTONES PRESENT'
   3
               = 'GALLBLADDER ENLARGED'
   4
               = 'BOTH'
   5
               = 'NORMAL';
 VALUE F78RPT
   1
               = 'YES'
   2
               = 'NO';
  *
      FORMAT MMDDYY8.
            SONO SONO.
            F78RPT F78RPT.;
RUN;
QUIT;
```

5

Num

8

F78VDATE ------ VERSION DATE DELETED type: numeric (int) units: . coded missing: 601 / 601 range: [.,.] unique values: O tabulation: Freq. Value Value missing for all patients. SONO ------ SONOGRAM RESULTS type: numeric (float) label: SONO range: [1,5] units: 1 values: 5 coded missing: 0 / 601 unique values: 5 tabulation: Freq. Numeric Label 32 1 ABNORMAL ? 230 2 GALLSTONES PRESENT 3 GALLBLADDER ENLARGED 8 4 BOTH 22 5 NORMAL 309 F78RPT ------ SONOGRAM REPORT RECEIVED type: numeric (float) label: F78RPT range: [1,2] units: 1 values: 2 coded missing: 319 / 601 unique values: 2 tabulation: Freq. Numeric Label 256 1 YES 26 2 NO F78FORM ------ FORM ON WHICH DATA WAS SENT IN type: numeric (float) range: [12,78] units: 1 /alues: 2 coded missing: 0 / 601 unique values: 2 tabulation: Freq. Value 386 12 215 78

_dta:

1. Created 10/28/99.

- MMMM.
 List of variables deleted
 ORCHDT
 F79INIT
 F79NDATE
 F79LASTU

 F79LASTE
 F79ESTAT
 F79VDATE
 F79FCB
 Image: Comparison of the comparison o
- TTTT. <u>New name</u> **JORCHDT**
- UUUU. Collection Information:

Form 79 (Oral Cholecystogram Report Form) was to be filled out whenever a study oral cholecystogram was completed. This test (or a sonogram) was required for patients entered between 25-30 years of age and patients who turned 25 before August 1983 if a plain film of the abdomen was negative (or equivocal) for gallstones. In 1983, it was decided that oral cholecystograms were acceptable only if they showed gallstones. If an oral cholecystogram was done and showed no stones, a sonogram was required. If an oral cholecystogram was done at the time of a right upper quadrant (RUQ) event, results may be collected on Form 34 (See Section 7.3.1).

VVVV. Data Collection Period: 03/79 - 11/84

WWWW. Form Version Dates: 02/02/84

XXXX. Files Used to Store Information:

SAS System Files: R79.SD2

Format Files: **R79.FMT**

YYYY. <u>Unique Record Identifiers</u>: **ANONID**, **ORCHDT** Records within the dataset are sorted by **ANONID** and **ORCHDT**

ZZZZ. Number of Observations (Patients) in SAS Dataset: 191 (189)

AAAAA. <u>Contents of SAS Dataset</u>:

- Alphabetical Listing of Variables: See p. 1
- Listing of Variables by Position: See p. 2
- BBBBB. Notes About Selected Variables: None

CCCCC. <u>Computed Variables</u>: None

DDDDD. <u>Inter-Relationship With Other Datasets</u>:

Other sources of information for gallstone data are

Phase 1 Forms	SAS Dataset	See Section
"Roster"	R09.SD2	1.0 (variables: PFLMSTAT , SONOGRAM)
77	R77.SD2	6.6.1
78	R78.SD2	6.6.2
10	R10.SD2	2.3
17, 19, 21, 24	R1722.SD2	4.5
25	R25.SD2	4.6
34	R34.SD2	7.3.1
83	R83.SD2	9.1

CONTENTS OF SAS DATASET: R79.SD2DATA FROM CSSCD FORM 78 - ORAL CHOLECYSTOGRAM REPORT FORMVARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
IN THE SAS DATASET AND ON FORMThe SAS System10:22 Tuesday, October 31, 2006

The CONTENTS Procedure

Data Set Name	OUT1.R79		Observations	191
Member Type	DATA		Variables	6
Engine	V9		Indexes	0
Created	14:18 Wednesday, Octobe	er 25, 2006	Observation Length	48
Last Modified	14:18 Wednesday, Octobe	er 25, 2006	Deleted Observations	0
Protection			Compressed	NO
Data Set Type			Sorted	NO
Label				
Data Representation	WINDOWS			
Encoding	wlatin1 Western (Winde	ows)		

Engine/Host Dependent Information

Data Set Page Size	4096
Number of Data Set Pages	3
First Data Page	1
Max Obs per Page	84
Obs in First Data Page	49
Number of Data Set Repairs	0
File Name	r79.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Туре	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
5	F79FORM	Num	8	FORM ON WHICH DATA WAS SENT IN
4	F79RPT	Num	8	ORAL CHOL REPORT RECEIVED
6	JORCHDT	Num	8	

SECTION 6.3 CHEST, SHOULDER< HIP X-RAY REPORT FORM

FORM	75
------	----

```
ORCH
  3
             Num
                   8
                       ORAL CHOL. RESULTS
     ORCSD
                   8
                       ORAL CHOL. SINGLE OR DOUBLE
  2
             Num
*****
* R79.fmt contains value labels for numerical codes assigned to
categorical *
* variables in the SAS dataset R79.SD2
****;
* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 10/28/99 14:40:30;
PROC FORMAT;
  VALUE ORCSD
               = 'SINGLE'
   1
               = 'DOUBLE';
   2
 VALUE ORCH
   1
               = 'ABNORMAL ?'
   2
               = 'GALLSTONES PRESENT'
               = 'GALLBLADDER NONFUNC.'
   3
   4
               = 'BOTH'
   5
               = 'NORMAL';
 VALUE F79RPT
               = 'YES'
   1
   2
               = 'NO';
*
  FORMAT
            MMDDYY8.
            ORCSD ORCSD.
            ORCH ORCH.
            F79RPT F79RPT.;
```

RUN; QUIT; F79VDATE ------ VERSION DATE DELETED type: numeric (int) range: [.,.] units: . /alues: 0 coded missing: 191 / 191 unique values: O tabulation: Freq. Value Value missing for all patients. ORCSD ----- ORAL CHOL. SINGLE OR DOUBLE type: numeric (float) label: ORCSD range: [1,2] units: 1 unique values: 2 coded missing: 66 / 191 tabulation: Freq. Numeric Label 67 1 SINGLE 2 DOUBLE 58 ORCH ----- ORAL CHOL, RESULTS type: numeric (float) label: ORCH range: [1,5] units: 1 /alues: 5 coded missing: 0 / 191 unique values: 5 tabulation: Freq. Numeric Label 141ABNORMAL ?372GALLSTONES PRESENT63GALLBLADDER NONFUNC.124BOTH1225NORMAL F79RPT ------ ORAL CHOL REPORT RECEIVED type: numeric (float) label: F79RPT range: [1,2] units: 1 unique values: 2 coded missing: 175 / 191 tabulation: Freq. Numeric Label . 11 1 YES 5 2 NO

F79FORM ------ FORM ON WHICH DATA WAS SENT IN

SECTION 6.3 CHEST, SHOULDER< HIP X-RAY REPORT FORM

type:	numeri	c (float)		
range:	[12,79]		units:	1
unique values:	2		coded missing:	0 / 191
tabulation:	Freq.	Value		
	186	12		
	5	79		

_dta:

1. Created 10/28/99.