CSSCD Phases 2 and 3 3.2: Cerebrovascular Accident Event Form – Form CVA

QUESTION-BY-QUESTION SPECIFICATIONS FOR THE CVA EVENT FORM

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

Question 2. CSSCD code number of person completing form: The code number of the person completing the CVA Event Form is to be assigned by the Data Coordinator at each clinic.

Question 3. Date of CVA: The date the CVA occurred should be entered in the MM/DDIYY date format (e.g., October24, 1994, would be entered 10/24/94).

Question 5. Type of CVA: Place a check mark in the box that corresponds to the type of OVA that the patient experienced (1. TIA, 2. Occlusive stroke, 3. Hemorrhagic stroke)

Question 6. Was patient hospitalized for this event? Place a check mark in the appropriate 1. NO or 2. YES box. If the response to Question 6 is 2. YES, questions 6.1 and 6.2 MUST be answered.

Question 6.1. Date of hospital admission: The date the of the hospital admission should be entered in the MM/DD/YY date format (e.g., October 24, 1994, would be entered 10/24/94).

Question 6.2. Date of hospital discharge: The date the of the hospital discharge should be entered in the MM/DD/YY date format (e.g., October 24, 1994, would be entered 10/24/94).

Question 7. Was the patient transfused within the 6 months preceding this event? Place a check mark in the appropriate 1. NO or 2. YES box. If the response to Question 7 is 2.YES, questions 7.1 and 7.2 MUST be answered.

Question 7.1. %A immediately prior to the first transfusion for this CVA?: If the patient was transfused within 3 months preceding the date of the CVA (i.e., the response

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to Question 7 is 2. YES), a blood sample should be drawn to measure the patient's percentage of hemoglobin A BEFORE (s)he receives the first transfusion for the CVA recorded on this form. Record the percentage of hemoglobin A in the boxes to the right of Question 7.1 and hemoglobin in the boxes to the right of Question 7.2.

Question 8. Did any of the following occur during the week prior to the CVA?: Ask the person being interviewed about each one of the following conditions listed in Question 8 A - A. Loss of consciousness, B. Change in mental status, 0. Loss of or difficulty with speech, D. Paralysis or weakness, E. Difficulty with swallowing, F. Difficulty with vision, G. Loss of balance or dizziness, H. Seizure, I. Headache. For example: "In the week prior to her CVA, did Karen experience a loss of consciousness?", "In the week prior to her CVA, did Karen experience a loss of or difficulty with speech?" etc. Place a check mark in the appropriate 1. NO or 2. YES box. Be sure to answer 1. NO or 2. YES to each of A - I for Question 8.

Question 9. Did any of the following occur the week prior to the CVA?: Ask the person being interviewed about each one of the conditions listed in Question 9 A - F: A. Acute febrile illness, B. Painful event, C. Acute Chest Syndrome, D. Acute anemia, E. General anesthesia, F. Priapism. For example: "In the week prior to her CVA, did Karen experience an acute febrile event?" "In the week prior to her CVA, did Karen experience a painful event?" etc. Place a check mark in the appropriate 1. NO or 2. YES box. Be sure to answer 1. NO or 2. YES to each of A - F for Question 9. For Question 9.F. Priapism, if the patient is female, DO NOT place a check mark in either response box. Instead, write "N/A -female" to the left of the response boxes. If the response to ANY of 9. A - F is 2. YES, be sure to complete a NON-CVA Event Form for each corresponding 2. YES response for which the patient was seen by medical personnel.

Question 10. RESULTS OF IMAGING TESTS: Place a check mark in the appropriate 1. NORMAL, 2. ABNORMAL or 3. NOT DONE box for each test listed: A. MRI of brain, B. CT scan of brain, C. PET scan of brain, D. MRA of brain, E. Transcranial Doppler, F. Arteriogram. Attach copies of ALL institutional reports for ALL imaging tests performed to the CVA Event Form.

Question 11. Was a CSSCD Neurological Evaluation Form completed?: Place a

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check mark in the appropriate 1. NO or 2. YES box. If the response to Question 11 is 2. YES, be sure to submit the NEUROLOGICAL EVALUATION FORM(S) to the SCC along with the CEREBROVASCULAR EVENT FORM.

Question 12. Were there other events associated with this CVA?: Place a check mark in the appropriate 1. NO or 2. YES box. If the response to Question 12 is 2. YES, a SEPARATE NON-CVA EVENT FORM MUST be completed for EACH unique associated event.

Question 13. Was the patient transfused for this event?: Place a check mark in the appropriate 1. NO or 2. YES box. If the response to Question 13 is 2. YES, a TRANSFUSION FORM MUST be completed for EACH transfusion given in association with this event.

Question 14. Did the patient die as a complication of this event?: Place a check mark in the appropriate 1. NO or 2. YES box. If the response to Question 14 is 2. YES, a CAUSE OF DEATH FORM MUST be completed.

CSSCD INFANT COHORT PATIENTS

CONTENTS OF SAS DATASET: CVA_PUBN.SD2

DATA FROM CSSCD FORM CVA - CEREBROVASCULAR ACCIDENT (CVA) EVENT FORM VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION IN THE SAS DATASET AND ON FORM CVA

DATE VARIABLES HAVE BEEN REMOVED & CSSCD ID #S REPLACED W/ ANONYMIZED ID #

The SAS System 13:51 Monday, March 15, 2004

The CONTENTS Procedure

Data Set Name: IN.CVA PUBN Observations: Member Type: DATA Variables: 37 Indexes: Engine: ٧6 0 13:55 Monday, March 15, 2004 Observation Length: 291 Last Modified: 13:55 Monday, March 15, 2004 Deleted Observations: 0 Protection: Compressed: NO Data Set Type: Sorted: NO Label:

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

Data Set Page Size: 16384
Number of Data Set Pages: 1
First Data Page: 1
Max Obs per Page: 56
Obs in First Data Page: 25
Number of Data Set Repairs: 0

File Name: cva_pubn.sd2
Release Created: 6.08.00
Host Created: WIN

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

#	Variable	Type	Len	Pos	Format	Informat	Label
38	ADJUDIC	Num	8	283			ADJUDICATED EVENT?
1	ANONID	Char	8	0			ANONYMIZED ID #
22	CVACANEM	Num	8	161	2.	2.	9D HAD ACUTE ANEMIA IN WEEK PRIOR TO CVA
21	CVACCHSY	Num	8	153	2.	2.	9C HAD ACUTE CHEST IN WEEK PRIOR TO CVA
19	CVACFEV	Num	8	137	2.	2.	9A HAD ACUTE FEBRILE EV IN WEEK PRIOR TO
29	CVART	Num	8	217	2.	2.	10E RESULTS OF ARTERIOGRAM
3	CVBNO	Num	8	9	3.	3.	DATA ENTRY BATCH NUMBER
9	CVCBCHB	Num	8	57	4.	4.1	72 HB IMMED PRIOR TO 1ST TX FOR THIS CVA
11	CVCMENT	Num	8	73	2.	2.	8B CHANGE IN MENTAL STATUS WEEK PRIOR TO
10	CVCONS	Num	8	65	2.	2.	8A LOST CONSCIOUSNESS WEEK PRIOR TO CVA
26	CVCTSCN	Num	8	193	2.	2.	10B RESULTS OF CT SCAN OF BRAIN
34	CVDIE	Num	8	257	2.	2.	14 DIE AS RESULT OF COMPLICATION OF CVA
16	CVDIZZ	Num	8	113	2.	2.	8G LOST BALANCE/WAS DIZZY WEEK PRIOR TO
32	CVEVENT	Num	8	241	2.	2.	12 OTHER EVENTS ASSOCIATED W/THIS CVA
23	CVGENANT	Num	8	169	2.	2.	9E HAD GENERAL ANESTHESIA WEEK PRIOR TO
18	CVHACHE	Num	8	129	2.	2.	8I HAD HEADACHE IN WEEK PRIOR TO CVA
8	CVHBA	Num	8	49	5.1	5.1	71 %A IMMED PRIOR TO 1ST TX FOR THIS CVA
6	CVHOSP	Num	8	33	2.	2.	6 WAS PT HOSPITALIZED FOR THIS EVENT
28	CVMRA	Num	8	209	2.	2.	10D RESULTS OF MRA OF BRAIN
25	CVMRI	Num	8	185	2.	2.	10A RESULTS OF MRI OF BRAIN
31	CVNEUEVL	Num	8	233	2.	2.	11 WAS CSSCD NEURO EVAL FORM COMPLETED
36	CVOVERS	Char	2	273			VERSION DATA TRANSCRIBED FROM
20	CVPAINEV	Num	8	145	2.	2.	9B HAD PAIN EVENT IN WEEK PRIOR TO CVA
13	CVPARAL	Num	8	89	2.	2.	8D PARALYSIS/WEAKNESS WEEK PRIOR TO CVA

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27	CVPETSCN	Num	8	201	2.	2.	10C RESULTS OF PET SCAN OF BRAIN
24	CVPRIAP	Num	8	177	2.	2.	9F HAD PRIAPISM IN WEEK PRIOR TO CVA
17	CVSEIZ	Num	8	121	2.	2.	8H HAD SEIZURE IN WEEK PRIOR TO CVA
12	CVSPDIF	Num	8	81	2.	2.	8C LOSS/DIFFICULTY W/SPEECH WK PRIOR TO
14	CVSWDIF	Num	8	97	2.	2.	8E DIFFICULTY W/SWALLOWING WEEK PRIOR TO
30	CVTCD	Num	8	225	2.	2.	10F RESULTS OF TRANSCRANIAL DOPPLER
7	CVTRANS	Num	8	41	2.	2.	7 PT TRANSFUSED W/IN 3 MOS BEFORE EVENT
33	CVTRANSN	Num	8	249	2.	2.	13 WAS PATIENT TRANSFUSED FOR THIS CVA
35	CVTRNSC	Num	8	265	2.	2.	DATA TRANSCRIBED FROM OLDER VERSION
5	CVTYPE	Num	8	25	2.	2.	5 TYPE OF CVA
2	CVVERS	Char	1	8			FORM VERSION
15	CVVISDIF	Num	8	105	2.	2.	8F DIFFICULTY W/VISION WEEK PRIOR TO CVA
4	CVWHERE	Num	8	17	2.	2.	4 WHERE WAS PT SEEN FOR THIS EVENT

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```
* CVAN.FMT contains value labels for numerical codes assigned *
* to catergorical variables in the SAS dataset CVA_PUBN.SD2
******************
PROC FORMAT;
VALUE CVWHERE 1='CSSCD CENTER'
               2='OTHER';
VALUE CVTYPE
              1='TIA'
               2='INFARCTIVE STROKE'
               3='CEREBRAL HEMORRHAGE';
*Format NO_YES used for the following variables: ADJUDIC CVHOSP CVTRANS CVCONS
                          CVCMENT CVSPDIF CVPARAL CVSWDIF CVVISDIF CVDIZZ CVSEIZ
                          CVHACHE CVACFEV CVPAINEV CVACCHSY CVACANEM CVGENANT
                           CVPRIAP CVNEUEVL CVEVENT CVTRANSN CVTRNSC CVDIE;
VALUE NO_YES
              1 = ' NO '
               2='YES';
*Format IMAGING used for the following variables: CVMRI CVCTSCN CVPETSCN CVMRA
                                                CVART CVTCD;
VALUE IMAGING 1='NORMAL'
               2='ABNORMAL'
               3='NOT DONE';
 FORMAT
               CVWHERE CVWHERE. CVTYPE CVTYPE. ADJUDIC CVHOSP CVTRANS
               CVCONS CVCMENT CVSPDIF CVPARAL CVSWDIF CVVISDIF CVDIZZ CVSEIZ
               CVHACHE CVACFEV CVPAINEV CVACCHSY CVACANEM CVGENANT CVPRIAP CVNEUEVL
               CVEVENT CVTRANSN CVDIE CVTRNSC NO YES.
               CVMRI CVCTSCN CVPETSCN CVMRA CVART CVTCD IMAGING.;
RUN;
QUIT;
```

CSSCD INFANT COHORT PATIENTS

type: string (str1)

unique values: 1 coded missing: 0 / 25

tabulation: Freq. Value 25 "C"

CVWHERE ----- 4 WHERE WAS PT SEEN FOR THIS EVENT

type: numeric (float)

label: CVWHERE

range: [1,2] units: 1 values: 2 coded missing: 0 / 25 unique values: 2

tabulation: Freq. Numeric Label

20 1 CSSCD CENTER 5 2 OTHER

CSSCD INFANT COHORT PATIENTS

CVTYPE ----- 5 TYPE OF CVA type: numeric (float) label: CVTYPE range: [1,3] units: 1 unique values: 3 coded missing: 0 / 25 tabulation: Freq. Numeric Label 9 1 TIA 12 2 INFARCTIVE STROKE 4 3 CEREBRAL HEMORRHAGE 9 CVTYPE: 1. Local diagnosis 2. See section B3.3 for adjudication decision ADJUDIC ----- ADJUDICATED EVENT? type: numeric (float) label: ADJUDIC range: [1,2]
unique values: 2 units: 1 coded missing: 0 / 25 tabulation: Freq. Numeric Label 4 1 NO 2 YES 21 ADJUDIC: 1. See section B3.3 for adjudication decision CVHOSP ----- 6 WAS PT HOSPITALIZED FOR THIS EVENT type: numeric (float) label: CVHOSP range: [1,2] unique values: 2 units: 1 coded missing: 0 / 25 tabulation: Freq. Numeric Label 6 1 NO 19 2 YES CVTRANS ----- 7 PT TRANSFUSED W/IN 3 MOS BEFORE EVENT type: numeric (float) label: CVTRANS range: [1,2] units: 1
values: 2 coded missing: 1 / 25 unique values: 2 tabulation: Freq. Numeric Label 16 1 NO 2 YES 8

CSSCD INFANT COHORT PATIENTS

CVHBA ----- 71 %A IMMED PRIOR TO 1ST TX FOR THIS CVA type: numeric (float) range: [33,46] units: 1 coded missing: 23 / 25 unique values: 2 tabulation: Freq. Value 1 33 1 46 CVCBCHB ----- 72 HB IMMED PRIOR TO 1ST TX FOR THIS CVA type: numeric (float) range: [8.5,14] units.
coded missing: 18 / 25 unique values: 6 mean: 10.8143 std. dev: 1.8587 percentiles: 10% 25% 50% 75% 90% 8.5 9.8 10.4 12.6 14 CVCONS ----- 8A LOST CONSCIOUSNESS WEEK PRIOR TO CVA type: numeric (float) label: CVCONS range: [1,2] unique values: 2 units: 1 coded missing: 0 / 25 tabulation: Freq. Numeric Label 1 NO 24 1 2 YES CVCMENT ----- 8B CHANGE IN MENTAL STATUS WEEK PRIOR TO type: numeric (float) label: CVCMENT range: [1,2] units: 1 coded missing: 0 / 25 unique values: 2 tabulation: Freq. Numeric Label 20 1 NO 2 YES 5

CSSCD INFANT COHORT PATIENTS

CVSPDIF ----- 8C LOSS/DIFFICULTY W/SPEECH WK PRIOR TO type: numeric (float) label: CVSPDIF range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25 tabulation: Freq. Numeric Label 1 NO 2 YES 20 5 CVPARAL ----- 8D PARALYSIS/WEAKNESS WEEK PRIOR TO CVA type: numeric (float) label: CVPARAL range: [1,2] units: 1 values: 2 coded missing: 0 / 25 unique values: 2 tabulation: Freq. Numeric Label 15 1 NO 10 2 YES CVSWDIF ----- 8E DIFFICULTY W/SWALLOWING WEEK PRIOR TO type: numeric (float) label: CVSWDIF range: [1,1] unique values: 1 units: 1 coded missing: 0 / 25 tabulation: Freq. Numeric Label 25 1 NO CVVISDIF ----- 8F DIFFICULTY W/VISION WEEK PRIOR TO CVA type: numeric (float) label: CVVISDIF range: [1,2] unique values: 2 units: 1 coded missing: 0 / 25 tabulation: Freq. Numeric Label 23 1 NO 2 2 YES

CSSCD INFANT COHORT PATIENTS

CVDIZZ ------ 8G LOST BALANCE/WAS DIZZY WEEK PRIOR TO

type: numeric (float)

label: CVDIZZ

range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25

tabulation: Freq. Numeric Label

17 1 NO 8 2 YES

CVSEIZ ------ 8H HAD SEIZURE IN WEEK PRIOR TO CVA

type: numeric (float)

label: CVSEIZ

range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25

tabulation: Freq. Numeric Label
22 1 NO
3 2 YES

CVHACHE ------ 8I HAD HEADACHE IN WEEK PRIOR TO CVA

type: numeric (float)

label: CVHACHE

range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25

tabulation: Freq. Numeric Label 16 1 NO

9 2 YES

CSSCD INFANT COHORT PATIENTS

CVACFEV ----- 9A HAD ACUTE FEBRILE EV IN WEEK PRIOR TO type: numeric (float) label: CVACFEV range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25 tabulation: Freq. Numeric Label 24 1 NO 1 2 YES CVPAINEV ----- 9B HAD PAIN EVENT IN WEEK PRIOR TO CVA type: numeric (float) label: CVPAINEV range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25 tabulation: Freq. Numeric Label 22 1 NO 3 2 YES CVACCHSY ----- 9C HAD ACUTE CHEST IN WEEK PRIOR TO CVA type: numeric (float) label: CVACCHSY range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25 tabulation: Freq. Numeric Label 23 1 NO 2 2 YES CVACANEM ----- 9D HAD ACUTE ANEMIA IN WEEK PRIOR TO CVA type: numeric (float) label: CVACANEM range: [1,1]
unique values: 1 units: 1 coded missing: 0 / 25 tabulation: Freq. Numeric Label 25 1 NO

CSSCD INFANT COHORT PATIENTS

CVGENANT ----- 9E HAD GENERAL ANESTHESIA WEEK PRIOR TO type: numeric (float) label: CVGENANT range: [1,1] units: 1
values: 1 coded missing: 0 / 25 unique values: 1 tabulation: Freq. Numeric Label 25 1 NO CVPRIAP ----- 9F HAD PRIAPISM IN WEEK PRIOR TO CVA type: numeric (float) label: CVPRIAP range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25 tabulation: Freq. Numeric Label 1 NO 24 1 2 YES CVMRI ----- 10A RESULTS OF MRI OF BRAIN type: numeric (float) label: CVMRI range: [2,3] units: 1 coded missing: 0 / 25 unique values: 2 tabulation: Freq. Numeric Label 21 2 ABNORMAL 3 NOT DONE CVCTSCN ------ 10B RESULTS OF CT SCAN OF BRAIN type: numeric (float) label: CVCTSCN range: [1,3] units: 1 coded missing: 1 / 25 unique values: 3 tabulation: Freq. Numeric Label 1 NORMAL 2 ABNORMAL 3 NOT DONE 6 8 10

CSSCD INFANT COHORT PATIENTS

```
CVPETSCN ----- 10C RESULTS OF PET SCAN OF BRAIN
              type: numeric (float)
             label: CVPETSCN
             range: [1,3] units: 1 values: 3 coded missing: 0 / 25
       unique values: 3
         tabulation: Freq. Numeric Label
                     1 1 NORMAL
1 2 ABNORMAL
23 3 NOT DONE
CVMRA ----- 10D RESULTS OF MRA OF BRAIN
             type: numeric (float)
             label: CVMRA
             range: [1,3] units: 1 values: 3 coded missing: 0 / 25
       unique values: 3
         tabulation: Freq. Numeric Label
                     2 1 NORMAL
                      13
                           2 ABNORMAL
3 NOT DONE
                      10
CVART ----- 10E RESULTS OF ARTERIOGRAM
             type: numeric (float)
             label: CVART
             range: [2,3] units. .
values: 2 coded missing: 1 / 25
       unique values: 2
         tabulation: Freq. Numeric Label
                     2 2 ABNORMAL
                      22
                           3 NOT DONE
CVTCD ------ 10F RESULTS OF TRANSCRANIAL DOPPLER
              type: numeric (float)
             label: CVTCD
             range: [1,3] units.
values: 3 coded missing: 0 / 25
       unique values: 3
         tabulation: Freq. Numeric Label
                      1 1 NORMAL
                      1 2 ABNORMAL
23 3 NOT DONE
```

CSSCD INFANT COHORT PATIENTS

CVNEUEVL ----- 11 WAS CSSCD NEURO EVAL FORM COMPLETED type: numeric (float) label: CVNEUEVL range: [1,2] units: 1 values: 2 coded missing: 0 / 25 unique values: 2 tabulation: Freq. Numeric Label 21 1 NO 4 2 YES CVEVENT ----- 12 OTHER EVENTS ASSOCIATED W/THIS CVA type: numeric (float) label: CVEVENT range: [1,2] units:
values: 2 coded missing: 0 / 25 unique values: 2 tabulation: Freq. Numeric Label 20 1 NO 5 2 YES CVTRANSN ----- 13 WAS PATIENT TRANSFUSED FOR THIS CVA type: numeric (float) label: CVTRANSN range: [1,2] units: 1 coded missing: 0 / 25 unique values: 2 tabulation: Freq. Numeric Label 7 1 NO 18 2 YES CVDIE ------ 14 DIE AS RESULT OF COMPLICATION OF CVA type: numeric (float) label: CVDIE range: [1,2] units: 1 unique values: 2 coded missing: 0 / 25 tabulation: Freq. Numeric Label 23 1 NO 2 2 YES 23

CSSCD INFANT COHORT PATIENTS

CVTRNSC ----- DATA TRANSCRIBED FROM OLDER VERSION

type: numeric (float)

label: CVTRNSC

units: 1 range: [1,2]

coded missing: 0 / 25 unique values: 2

tabulation: Freq. Numeric Label

1 NO 24 2 YES 1

CVOVERS ------ VERSION DATA TRANSCRIBED FROM

type: string (str2)

unique values: 2 coded missing: 0 / 25

tabulation: Freq. Value 1 "-1"

24 "-7"

_dta:

1. Created 03/03/2000