

**CSSCD Phases 2 and 3**  
**3.1: Non-CVA Event Form – Form NCVA**

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**QUESTION-BY-QUESTION SPECIFICATIONS FOR THE NON-CVA EVENT FORM**

**Question 1. Person completing form:** The person completing the NON-CVA 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 form is to be assigned by the Data Coordinator at each clinic.

**Question 3. Date form completed:** The date the form was completed should be entered in the MM/DDYY date format (e.g., October 24, 1994, would be entered 10/24/94).

**Question 4. Date of event:** The date the event occurred should be entered in the MM/DD/YY date format (e.g., October 24, 1994, would be entered 10/24/94).

**Question 5. Event name:** Refer to the event choices listed below and write in the event type (name) - i.e., DO NOT just enter the code number of the event; the name of the event MUST be written in.

<b>EXAMPLE</b>
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5. Event Name (see choices below):

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OFFICE  
USE

**044 Bilateral Otitis Media**

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If SPECIFY TYPE is written next to the event, be sure to specify the type of event (e.g., 090 Surgery - Cholecystectomy)

Refer to pages 4-6 for definitions of the event types listed.

There are some special guidelines for reporting chronic events. An event form must be completed for newly diagnosed chronic events and each newly diagnosed site of involvement regardless of whether or not the patient is hospitalized. In addition, whether the chronic condition is newly diagnosed or not, an event form must be completed each

**CSSCD Phases 2 and 3**  
**3.1: Non-CVA Event Form – Form NCVA**

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time a patient is admitted to the hospital because of the chronic condition. The specific reason for hospitalization should be listed as the response for Question 5 (e.g., acute flare up of aseptic necrosis of L. hip, infected leg ulcer (previously diagnosed)). In summary, a NON-CVA EVENT FORM should be completed for the first occurrence of a chronic event AND for all admissions for a chronic event. NON-CVA EVENT FORMS are NOT required for scheduled outpatient transfusions (see Section 9.3) or renal dialysis. However, if a patient is hospitalized and the only reason the patient was admitted was to receive a transfusion or dialysis, a NON-CVA EVENT FORM should be completed.

**Question 6. Has the patient been seen for the same type of event within the preceding week?:** Place a check mark in the appropriate box, 1. NO or 2. YES. If Question 6 is answered 2. YES, you must complete question 6.1.

**Question 6.1 Do the present history, symptoms, and/or physical exam indicate that this event is a continuation of the previous event?:** Place a check mark in the appropriate box, 1. NO, 2. YES, or 9. DK.

**Question 7. Was the patient admitted to the hospital because of this event?:** Place a check mark in the appropriate box, 1. NO or 2. YES. If the reason for the patient's admission to the hospital was because of the event listed in Question 5, check the 2. YES box. However, if the patient was not admitted to the hospital for the event listed in Question 5, OR the patient was already in the hospital for another event at the time of this event, check the 1. NO box. If Question 7 is answered 2. YES, you must complete questions 7.1 and 7.2.

**Question 7.1. 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 7.2. 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).

**CSSCD Phases 2 and 3**  
**3.1: Non-CVA Event Form – Form NCVA**

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**Question 8. Were the samples for any of the following cultures obtained?:** Place a check mark in the appropriate (1. NO or 2. YES) box for each of 8.1 A-D. If the response is 2. YES, place a check mark in the appropriate corresponding (8.2 A-D) results (1. NEGATIVE or 2. POSITIVE) box. If the response for any of 8.2 A-D is 2. POSITIVE, write in the organism name on the corresponding line (8.3 A-D). If the response to 8.1.D is 2. YES, write in the source for the culture on the 8.1.D1 specify line—e.g., STOOL.

**Question 9: Were any serological studies performed?:** Place a check mark in the appropriate (1. NO or 2. YES) box. If the response is 2. YES, list the serological studies on lines 9.1A-C and place a check mark in the appropriate corresponding (9.2A-C) results (1. NEGATIVE or 2. POSITIVE) box.

**Question 10. Were there other events associated with this event?:** Place a check mark in the appropriate box, 1. NO or 2. YES. If Question 10.1 is answered 2. YES, be sure to complete a separate event form for each event. If the response to question 7 is 1. NO because the patient was already in the hospital for some other reason, then check the 2. YES box, and complete a separate event form for the event for which the patient was originally hospitalized.

**Question 11. Did the patient require ventilator support?:** Place a check mark in the appropriate box, 1. NO or 2. YES. If Question 11 is answered 2. YES, record the number of days ventilator support was required (Question 11.1).

**Question 12. Was the patient transfused for this event?:** Place a check mark in the appropriate box, 1. NO or 2. YES. If Question 12 is answered 2. YES, be sure to complete a separate TRANSFUSION FORM for each transfusion the patient received.

**Question 13. Did the patient die as a result of this event?:** Place a check mark in the appropriate box, 1. NO or 2. YES. If Question 13 is answered 2. YES, be sure to complete a CAUSE OF DEATH FORM.

**CSSCD Phases 2 and 3**  
**3.1: Non-CVA Event Form – Form NCVA**

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Definitions of selected clinical events and medical conditions

**Painful Episode**

1. Pain in the extremities, back, abdomen, chest, or head, for which no other explanation can be found and which is not classified as one of the other special events.
2. RESTRICTION – Pain shall have lasted for at least 2 hours.
3. Irritability in young children accompanied by pain on palpation is considered appropriate evidence.
4. RESTRICTION – If patient is old enough, he/she must have stated that pain is of nature usually associated with a crisis.

**Skeletal & Joint Events**

Bone Infarction and/or Osteomyelitis: An acute, painful episode, involving one or more bones, that has lasted at least seven days.

Osteomyelitis: Skeletal and joint event with identification of an etiologic agent by culture.

Joint Swelling with Effusion: Swelling of one or more joints with pain or effusion not due to trauma in the last three days.

**Acute Chest Syndrome**

1. A new pulmonary infiltrate which is demonstrable on a chest x-ray or by an isotope scan of the lungs, or
2. Evidence of pleuritic chest pain, with or without dyspnea, in the absence of a pulmonary infiltrate on the chest x-ray. If pleuritic pain is limited to the chest and chest films are negative, then a perfusion lung scan is required.

Any episodes where the chest films, scan and other pertinent tests did not indicate a new lesion were to be followed as painful crisis (Form 30 – See Section 7.1.0).

**Right Upper Quadrant Syndrome**

Any two of the following:

1. Pain only in the right upper quadrant of the abdomen
2. A two-fold increase in total bilirubin over baseline\*
3. A two centimeter increase in liver size over baseline\*
4. A two-fold increase in SGOT over baseline\*

\*baseline or “steady-state” values for bilirubin, SGOT, and liver size were defined as the lowest of the values recorded at preceding regularly scheduled study visits when the patient was not experiencing an acute event.

**Hand-Foot Syndrome**

Pain and tenderness, with or without swelling, in the hands and/or feet in an individual in the pediatric age group (age < 10 years).

**Seizures**

Seizure: Major or minor motor seizures or psychomotor seizures which are not secondary to central nervous system infection, tumor, or stroke.

**CSSCD Phases 2 and 3**  
**3.1: Non-CVA Event Form – Form NCVA**

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Seizure disorder: Transient electrical abnormality of a localized area of the brain resulting in involuntary movements, altered perception, or altered state of consciousness.

**Meningitis**

Inflammation of the meninges caused by an infectious agent as demonstrated by lumbar puncture abnormalities and cultures.

**Cerebrovascular Accident (CVA)**

Acute neurologic syndrome secondary to occlusion of an artery or hemorrhage with resultant ischemic and neurologic symptoms and signs.

Cerebrovascular accidents were to be classified into one of the following three categories:

1. Transient Ischemic Attack (TIA): Neurologic signs with vascular distribution that clear within 24 hours (48 hours if basilar system is involved).
2. “Thrombotic” (infarctive): Completed stroke due to occlusion of vessel(s) by thrombus or embolus or to vessel spasm.
3. “Hemorrhagic” (intracerebral hemorrhage): Completed stroke due to hemorrhage (e.g., subarachnoid, subdural, intracerebral, aneurysm).

**Acute Anemic Episode**

A reduction in hemoglobin or hematocrit of at least 30% not caused by blood loss or a transfusion reaction, or reduction of hemoglobin level by 20% accompanied by acute increase in spleen size.

Acute anemic events were to be classified into one of the following three categories:

1. Splenic sequestration crisis: Increase in spleen size and firmness, reduction of hemoglobin level by at least 20%.
2. Aplastic crisis: Decrease in reticulocyte count before or concurrent with falling hemoglobin level ( $\geq 30\%$  reduction from usual level), fall in platelet count and white cell count in prolonged aplasia, and appearance of increased nucleated red cells and reticulocytes in peripheral blood as the marrow recovers.
3. Hyperhemolytic crisis: Normal or increased reticulocyte counts and nucleated RBC counts during an episode of falling hemoglobin and increase in indirect bilirubin level over the usual value.

**Acute Febrile Event**

Elevation of temperature greater than 38.3 degrees centigrade orally or 38.9 degrees rectally which was documented by medical personnel.

**Bacteremia/Septicemia**

Acute febrile event with positive blood culture.

**Priapism**

Acute Priapism: A painful erection in the penis lasting more than one hour.

Chronic Priapism:

1. A semi-erection of the penis which has not completely disappeared for a month (originally diagnosed as acute priapism), or

**CSSCD Phases 2 and 3**  
**3.1: Non-CVA Event Form – Form NCVA**

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2. More than one episode of acute priapism.

**Renal Complications**

1. Hematuria: A history of gross hematuria confirmed by a member of the medical team or > 20 RBC/HPF from urinalysis.
2. Urinary Tract Infection: > 20 WBC/HPF in an uncontaminated clean catch urine specimen or urine culture resulting in the growth of more than 10<sup>5</sup> colonies/ml.
3. Persistent Proteinuria (nephrotic syndrome): 3+, 4+ protein reaction on two consecutive early AM urine specimens measured by dip stick on the absence of gross hematuria.
4. Renal Insufficiency:
  - A. *Prior to 10/82*: Two consecutive determinations of creatinine > 1.5 mg/dl for patients over 10 years of age, or > 0.8 for patients less than ten years of age, followed by creatinine clearance < 100 ml/min/1.73 m.
  - B. *After 10/82*: A 20% increase in serum creatinine followed by a two-hour creatinine clearance of < 100 cc/minute.

**Aseptic Necrosis**

Early radiographic findings of sub-epiphyseal lucency and widening of a joint space or late radiographic changes of flattening of the epiphysis and sclerosis with fragmentation.

**Leg Ulcers**

Ulceration of the skin of the lower legs, especially the medial or lateral surfaces, which fails to heal in a period of two weeks.

**Ocular Complications**

1. Suspected Stage III retinopathy (nonvascular capillary buds at the site of arteriolar-venular anatomoses),
2. A two line visual loss since the last examination, and
3. Changes in the macula.

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM**  
 CSSCD INFANT COHORT PATIENTS

CONTENTS OF SAS DATASET: NCVAPUBN.SD2  
 DATA FROM CSSCD FORM NCVA - NON-CVA EVENT FORM  
 VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION  
 IN THE SAS DATASET AND ON FORM NCVA  
 DATE VARIABLES HAVE BEEN REMOVED & CSSCD ID #S REPLACED W/ ANONYMIZED ID #

The SAS System 13:31 Friday, March 12, 2004 2

The CONTENTS Procedure

Data Set Name: IN.NCVAPUBN	Observations:	7656
Member Type: DATA	Variables:	43
Engine: V6	Indexes:	0
Created: 14:32 Friday, March 12, 2004	Observation Length:	449
Last Modified: 14:32 Friday, March 12, 2004	Deleted Observations:	0
Protection:	Compressed:	NO
Data Set Type:	Sorted:	NO
Label:		

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

Data Set Page Size: 16384  
 Number of Data Set Pages: 214  
 First Data Page: 1  
 Max Obs per Page: 36  
 Obs in First Data Page: 23  
 Number of Data Set Repairs: 0  
 File Name: ncva\_pun.sd2  
 Release Created: 6.08.00  
 Host Created: WIN

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

#	Variable	Type	Len	Pos	Format	Informat	Label
1	ANONID	Char	8	0			ANONYMIZED ID #
33	EVASEVNT	Num	8	345	2.	2.	10 OTHER EVNTS ASSOC. W/ THIS EVENT
11	EVBLDO	Char	20	73			83A ORGANISM IDENTIFIED IN BLOOD CULTURE
12	EVBLDOC	Num	8	93	4.	4.	BLOOD CULTURE ORGANISM CODE
10	EVBLDR	Num	8	65	2.	2.	82A BLOOD CULTURE RESULTS
9	EVBLDS	Num	8	57	2.	2.	81A BLOOD CULTURE DONE
4	EVBN0	Num	8	17	3.	3.	DATA ENTRY BATCH NUMBER
41	EVCULT	Num	8	403	2.	2.	WAS SPECIFIC ORGANISM IDENTIFIED (PH2)
25	EVCULTFR	Char	20	233			8D1 SOURCE OF OTHER CULTURE SPECIFY
37	EVDIE	Num	8	377	2.	2.	13 DID PT DIE AS RESULT OF THIS EVENT
8	EVHOSP	Num	8	49	2.	2.	7 ADMITTED TO HOSPITAL BECAUSE OF EVENT
5	EVICD1	Num	8	25	6.2	6.2	EVENT ICD-9 CODE 1
2	EVID2	Num	8	8	3.	3.	FOLLOW-UP IDENTIFIER
40	EVINFECT	Num	8	395	2.	2.	WAS THE EVENT AN INFECTION (PH2)
39	EVNOVERS	Char	2	393			VERSION DATA TRANSCRIBED FROM
38	EVNTRNSC	Num	8	385	2.	2.	DATA TRANSCRIBED FROM OLDER VERSION
43	EVORGC	Num	8	441	4.	4.	ORGANISM CODE (PH2)
42	EVORGN	Char	30	411			SPECIFY ORGANISM IDENTIFIED (PH2)
23	EVOTHO	Char	20	205			83D ORGANISM IDENTIFIED IN OTHER CULTURE
24	EVOTHOC	Num	8	225	4.	4.	OTHER CULTURE ORGANISM CODE
22	EVOTHR	Num	8	197	2.	2.	82D OTHER CULTURE RESULTS
21	EVOTHS	Num	8	189	2.	2.	81D OTHER CULTURE DONE
7	EVSAME	Num	8	41	2.	2.	61 IS THIS A CONTINUATION OF PREVIOUS EV
26	EVSER	Num	8	253	2.	2.	9 WERE SEROLOGICAL STUDIES PERFORMED

**CODEBOOK FOR CSSCD FORM NCVA**

**NON-CVA EVENT FORM**

CSSCD INFANT COHORT PATIENTS

27	EVSEFN1	Char	20	261			91A SEROLOGICAL STUDY 1 SPECIFY
29	EVSEFN2	Char	20	289			91B SEROLOGICAL STUDY 2 SPECIFY
31	EVSEFN3	Char	20	317			91C SEROLOGICAL STUDY 3 SPECIFY
28	EVSEFR1	Num	8	281	2.	2.	92A SEROLOGICAL STUDY 1 RESULTS
30	EVSEFR2	Num	8	309	2.	2.	92B SEROLOGICAL STUDY 2 RESULTS
32	EVSEFR3	Num	8	337	2.	2.	92C SEROLOGICAL STUDY 3 RESULTS
19	EVTHRO	Char	20	161			83C ORGANISM IDENTIFIED THROAT CULTURE
20	EVTHROC	Num	8	181	4.	4.	THROAT CULTURE ORGANISM CODE
18	EVTHRR	Num	8	153	2.	2.	82C THROAT CULTURE RESULTS
17	EVTHRS	Num	8	145	2.	2.	81C THROAT CULTURE DONE
36	EVTRANS	Num	8	369	2.	2.	12 WAS PT TRANSFUSED FOR THIS EVENT
15	EVURNO	Char	20	117			83B ORGANISM IDENTIFIED IN URINE CULTURE
16	EVURNOC	Num	8	137	4.	4.	URINE CULTURE ORGANISM CODE
14	EVURNR	Num	8	109	2.	2.	82B URINE CULTURE RESULTS
13	EVURNS	Num	8	101	2.	2.	81B URINE CULTURE DONE
34	EVVENT	Num	8	353	2.	2.	11 DID PT REQUIRE VENTILATOR SUPPORT
35	EVVENTD	Num	8	361	2.	2.	111 # OF DAYS PATIENT ON VENTILATOR
3	EVVERS	Char	1	16			FORM VERSION
6	EVW1WK	Num	8	33	2.	2.	6 PT SEEN FOR SAME EV IN WEEK PRECEDING



**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM**  
CSSCD INFANT COHORT PATIENTS

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

PROC FORMAT;

```
VALUE ID2F      10='10-VASOOCCLUSIVE PAIN'
                20='20-ACUTE CHEST SYNDROME'
                30='30-FEVER WITHOUT SOURCE'
                41='41-SEPSIS'
                42='42-MENINGITIS'
                43='43-OSTEOMYELITIS'
                44='44-OTHER INFECTION (SPECIFY TYPE)'
                50='50-CNS EVENT (UNSPECIFIED)'
                51='51-INFARCTIVE STROKE'
                53='53-SEIZURE'
                54='54-OTHER NEUROLOGICAL EVENT'
                60='60-ACUTE ANEMIA (UNSPECIFIED)'
                61='61-SPLENIC SEQUESTRATION'
                62='62-APLASTIC CRISIS'
                63='63-OTHER ANEMIA (SPECIFY TYPE)'
                70='70-RIGHT UPPER QUADRANT'
                80='80-PRIAPISM'
                90='90-SURGERY (SPECIFY TYPE)'
               100='100-NEW LEG ULCER'
               111='111-NEW ASEPTIC NECROSIS (HIP)'
               112='112-NEW ASEPTIC NECROSIS (SHOULDER)'
               120='120-RENAL COMPLICATION (NOT SPECIFIED BELOW)'
               121='121-URINARY TRACT INFECTION'
               122='122-HEMATURIA'
               123='123-PROTEINURIA'
               124='124-RENAL INSUFFICIENCY'
               150='150-DEATH'
               160='160-OTHER EVENT NOT SPECIFIED'
               161='161-OTHER EVENT NOT SPECIFIED';
```

```
*Format NO_YES used for the following variables: EVW1WK EVHOSP EVBLDS EVURNS
                                                    EVTHRS EVOTHS EVSER EVASEVNT
                                                    EVVENT EVDIE EVINFECT EVCULT;
```

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

```
VALUE EVSAME  1='NO'
              2='YES'
              9='DONT KNOW';
```

```
VALUE EVTRANS 1='NO'
              2='YES'
              8='NOT APPLICABLE - EVENT DEATH';
```

CODEBOOK FOR CSSCD FORM NCVA

NON-CVA EVENT FORM

CSSCD INFANT COHORT PATIENTS

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\*Format CX\_SERO used for the following variables: EVBLDR EVURNR EVTHRR EVOTHR  
EVSERR1 EVSERR2 EVSERR3;

VALUE CX\_SERO 1='NEGATIVE'  
2='POSITIVE';

FORMAT           EVID2 ID2F. EVW1WK EVHOSP EVBLDS EVURNS EVTHRS EVOTHS EVSER  
EVASEVNT EVVENT EVDIE EVNTRNSC EVINFECT EVCULT NO\_YES. EVSAME EVSAME.  
EVBLDR EVURNR EVTHRR EVOTHR EVSERR1 EVSERR2 EVSERR3 CX\_SERO.  
EVTRANS EVTRANS.;

RUN;  
QUIT;

CODEBOOK FOR CSSCD FORM NCVA

NON-CVA EVENT FORM

CSSCD INFANT COHORT PATIENTS

EVID2 ----- FOLLOW-UP IDENTIFIER

type: numeric (float)  
label: EVID2  
range: [10,161] units: 1  
unique values: 29 coded missing: 0 / 7656

tabulation:	Freq.	Numeric	Label
	3568	10	10-VASOOCCLUSIVE PAIN
	700	20	20-ACUTE CHEST SYNDROME
	946	30	30-FEVER WITHOUT SOURCE
	52	41	41-SEPSIS
	5	42	42-MENINGITIS
	7	43	43-OSTEOMYELITIS
	904	44	44-OTHER INFECTION (SPECIFY TYPE)
	2	50	50-CNS EVENT (UNSPECIFIED)
	9	51	51-INFARCTIVE STROKE
	21	53	53-SEIZURE
	16	54	54-OTHER NEUROLOGICAL EVENT
	43	60	60-ACUTE ANEMIA (UNSPECIFIED)
	43	61	61-SPLENIC SEQUESTRATION
	82	62	62-APLASTIC CRISIS
	8	63	63-OTHER ANEMIA (SPECIFY TYPE)
	77	70	70-RIGHT UPPER QUADRANT
	40	80	80-PRIAPISM
	140	90	90-SURGERY (SPECIFY TYPE)
	1	100	100-NEW LEG ULCER
	13	111	111-NEW ASEPTIC NECROSIS (HIP)
	2	112	112-NEW ASEPTIC NECROSIS (SHOULDER)
	13	120	120-RENAL COMPLICATION (NOT SPECIFIED BELOW)
	74	121	121-URINARY TRACT INFECTION
	18	122	122-HEMATURIA
	13	123	123-PROTEINURIA
	2	124	124-RENAL INSUFFICIENCY
	1	150	150-DEATH
	853	160	160-OTHER EVENT NOT SPECIFIED
	3	161	161-OTHER EVENT NOT SPECIFIED

EVID2:

1. Codes 50, 51, 52, and 54 not response choices on EVVERS='C'; see CVA codebook

EVVERS ----- FORM VERSION

type: string (str1)  
unique values: 2 coded missing: 0 / 7656

tabulation:	Freq.	Value
	3397	"C"
	4259	"H"

CODEBOOK FOR CSSCD FORM NCVA

NON-CVA EVENT FORM

CSSCD INFANT COHORT PATIENTS

EVICD1 ----- EVENT ICD-9 CODE 1 **MODIFIED**

type: numeric (float) units: .01  
 range: [2.2,999.8] coded missing: 5673 / 7656  
 unique values: 366  
 tabulation:

Freq.	Value	Freq.	Value	Freq.	Value	Freq.	Value
1	2.2	1	77.3	2	312.9	1	477.9
1	3	1	77.47	1	342.9	1	478.1
4	4.9	2	77.9	1	344.61	2	483
1	6	101	79.9	5	346.9	1	487
19	8.8	1	79.99	1	349.2	2	487.1
1	9	1	80.4	3	360	1	490
2	11.9	1	80.88	1	361.9	1	493
1	14.74	1	82.11	1	362.29	1	493.01
1	18.21	1	82.99	1	362.31	98	493.9
1	19.4	1	83.13	1	362.81	2	493.91
3	20.01	1	86.04	1	368.8	1	511.9
1	22.2	1	86.06	10	372.3	1	518
1	23.1	1	86.07	4	376.01	1	518.81
1	27	1	87.66	1	379.91	3	519.1
3	28.2	4	88.41	2	379.92	2	519.8
13	28.3	1	97.38	2	382	1	522.5
3	28.6	1	97.69	139	382.9	3	523.1
70	34	1	97.88	8	388.7	1	525.9
8	34.1	4	97.89	1	401.9	1	526.9
1	38.85	1	98	1	403.9	2	528
9	38.93	1	98.11	1	416	1	528.5
1	41	2	99	1	427.69	3	528.9
14	41.5	8	99.01	1	427.89	1	530.1
2	44	213	99.04	1	427.9	2	530.11
1	47.9	1	99.29	4	428	2	535.5
1	49.9	1	99.99	3	435.9	3	536.8
1	51	1	110	1	451	1	550.9
1	51.1	2	110.5	2	451.9	42	558.9
34	51.22	1	112.1	2	453.9	1	560.1
4	51.23	1	120	2	460	17	564
15	52.9	1	136.8	4	461	1	571.8
9	53	2	160	1	461.1	1	573.8
1	53.9	1	190	2	461.8	1	573.9
1	54.1	2	275.4	15	461.9	6	574
3	54.2	1	276.2	129	462	11	574.2
1	54.9	4	276.5	46	463	5	574.5
1	55.23	1	276.7	1	464	4	575
1	57.9	1	282.06	1	464.3	1	576.1
1	58.3	7	282.64	1	464.4	1	576.8
1	62.5	1	282.67	1	465	1	577
3	64	2	283	14	465.8	1	584.9
3	64.98	1	287.5	180	465.9	1	590.1
1	70.1	3	289.3	19	466	1	590.8
1	70.9	1	289.9	3	466.1	1	591
1	71.4	1	292.12	1	473	1	597.8
1	74.3	1	293	1	473.2	1	599
1	74.99	1	298.9	2	473.9	3	607.1
4	75	1	300.9	1	474	1	607.9
1	77.15	1	306.3	3	474.12	2	614.9

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM**  
 CSSCD INFANT COHORT PATIENTS

EVICD1(cont'd) ----- EVENT ICD-9 CODE 1

type: numeric (float)  
 range: [2.2,999.8] units: .01  
 unique values: 366 coded missing: 5673 / 7656

tabulation:

Freq.	Value	Freq.	Value	Freq.	Value	Freq.	Value
4	616.1	1	728.85	1	795.5	1	893
1	634.5	1	729.5	6	799	1	910
1	634.9	1	729.81	1	799.8	1	913
1	635.9	1	730.06	1	799.9	2	917
1	644.2	3	733.99	1	799.99	2	919.4
3	650	2	780	1	802	1	920
1	681	1	780.09	1	803.5	1	921.1
2	681.1	1	780.1	1	807	1	921.3
1	681.11	8	780.2	1	811.01	1	922.1
1	681.9	10	780.4	2	812.2	1	922.3
8	682	2	780.57	1	812.41	1	923.21
1	682.1	2	780.6	1	813.42	1	924.21
2	682.3	1	781.2	2	813.81	1	938
1	682.4	2	781.9	2	814	1	941.09
5	682.6	2	782	1	814.01	1	942.02
3	682.7	17	782.1	1	816	1	944.01
1	682.8	1	782.2	2	818	1	944.2
1	682.9	2	782.3	1	821	1	948
1	683	2	782.4	1	823.82	1	950
8	684	1	783.4	1	824.8	2	958.3
2	686	50	784	2	826	6	959
1	686.9	1	784.1	1	827	5	959.1
5	692.9	2	784.2	1	834	4	959.2
2	696.3	4	784.7	1	839.61	6	959.3
1	705.83	2	785.1	1	840.9	5	959.4
1	708	1	785.6	1	844.9	2	959.5
1	708.9	3	786.02	8	845	8	959.7
1	710	8	786.09	3	850.9	2	959.9
1	711.93	6	786.2	1	851.8	1	959.94
1	716.9	10	786.5	4	854	1	960.1
2	718.86	2	786.9	1	855	1	966.3
2	719.02	34	787	1	858.3	1	977.9
1	719.07	4	788.1	1	863.55	4	984.9
1	719.08	1	788.2	1	872.61	1	989.5
2	719.41	1	788.3	2	873	1	989.9
2	719.45	1	788.4	3	873.42	1	994.1
3	719.46	1	788.9	1	873.44	3	995.2
1	723.1	21	789	2	873.8	1	995.3
4	724.2	1	789.1	1	878.4	2	996.6
1	726.64	4	789.2	2	879.8	3	996.62
1	726.71	1	790.4	2	882	1	999
1	727	1	790.6	3	891	1	999.6
				2	892	5	999.8

EVICD1:

1. Required only if EVID2=44, 54, 63, 70, 90, 160, or 161
2. See ICD-9-CM CODEBOOK for code descriptions

CODEBOOK FOR CSSCD FORM NCVA

NON-CVA EVENT FORM

CSSCD INFANT COHORT PATIENTS

EVICD2 ----- EVENT ICD-9 CODE 2 DELETED

type: numeric (float)

range: [8.8,999.99]

units: .01

unique values: 84

coded missing: 7479 / 7656

tabulation:

Freq.	Value	Freq.	Value	Freq.	Value	Freq.	Value
4	8.8	4	276.5	1	527.2	1	785.2
1	17	1	333.2	1	536.8	4	786.09
2	20.01	1	337.9	1	536.9	2	786.2
1	22	2	372.3	7	558.9	3	786.5
1	28.3	2	379.93	5	564	7	787
4	34	9	382.9	1	570	1	787.1
1	40.3	1	386.3	1	575	1	788.1
2	47	1	437.5	3	577	3	789
1	50.11	1	461	1	588.9	1	799
2	51.51	6	461.9	1	719.06	1	808.8
1	51.97	8	462	1	719.42	2	819
2	54	1	463	1	726.7	1	845
2	54.21	1	464.1	1	729.5	1	854
1	64	1	465.8	1	780.2	1	906
1	75	7	465.9	3	780.4	2	910
1	77.17	1	466	6	780.6	1	912
5	79.9	2	478.1	1	781.3	1	920
1	87.53	1	486.2	1	782	1	936.1
1	90	1	490	1	782.4	4	959.1
1	97.89	1	493.9	6	784	1	959.6
1	275.4	3	519.1	2	784.2	1	999.99

EVICD2:

1. Required only if EVID2=44, 54, 63, 70, 90, 160, or 161 with more than one diagnosis or procedure
2. See ICD-9-CM CODEBOOK for code descriptions

EVW1WK ----- 6 PT SEEN FOR SAME EV IN WEEK PRECEDING

type: numeric (float)

label: EVW1WK

range: [1,2]

units: 1

unique values: 2

coded missing: 4 / 7656

tabulation:	Freq.	Numeric	Label
	7116	1	NO
	536	2	YES

CODEBOOK FOR CSSCD FORM NCVA

NON-CVA EVENT FORM

CSSCD INFANT COHORT PATIENTS

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EVSAE ----- 61 IS THIS A CONTINUATION OF PREVIOUS EV

type: numeric (float)

label: EVSAE

range: [1,9]

units: 1

unique values: 3

coded missing: 7120 / 7656

tabulation:	Freq.	Numeric	Label
	74	1	NO
	409	2	YES
	53	9	DONT KNOW

EVSAE:

1. Required only if EVW1WK=2

EVHOSP ----- 7 ADMITTED TO HOSPITAL BECAUSE OF EVENT

type: numeric (float)

label: EVHOSP

range: [1,2]

units: 1

unique values: 2

coded missing: 3 / 7656

tabulation:	Freq.	Numeric	Label
	3050	1	NO
	4603	2	YES

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
 CSSCD INFANT COHORT PATIENTS

EVBLDS ----- 81A BLOOD CULTURE DONE

```

      type: numeric (float)
      label: EVBLDS

      range: [1,2]                units: 1
      unique values: 2            coded missing: 4406 / 7656

      tabulation:  Freq.  Numeric  Label
                   1961      1     NO
                   1289      2     YES
  
```

EVBLDS:  
 1. Required only if EVVERS='C'

EVBLDR ----- 82A BLOOD CULTURE RESULTS

```

      type: numeric (float)
      label: EVBLDR

      range: [1,2]                units: 1
      unique values: 2            coded missing: 6383 / 7656

      tabulation:  Freq.  Numeric  Label
                   1206      1     NEGATIVE
                    67      2     POSITIVE
  
```

EVBLDR:  
 1. Required only if EVBLDS=2

EVBLDO ----- 83A ORGANISM IDENTIFIED IN BLOOD CULTURE

```

      type: string (str20)
      unique values: 28            coded missing: 0 / 7656
  
```

```

tabulation:
Freq.  Value                                Freq.  Value
  9    "."                                  5    "MIXED"
  1    "A"                                  1    "MYCOPLASMA"
7580  "C"                                  2    "NEISSERIA MENINGITID"
  4    "ACINETOBACTER"                     1    "PARVOVIRUS"
  1    "ACINETOBACTER LUOFFI"               3    "PSEUDOMONAS"
  2    "BHS-GRP A"                          6    "S. PNEUMONIAE"
  2    "BHS-GRP D"                          1    "SALMONELLA"
  1    "CANDIDA"                             1    "SALMONELLA, TYPE B"
  3    "E. COLI"                             10   "STAPH - COAG NEG"
  3    "GRAM + COCCI"                       4    "STAPH - COAG POS"
  2    "GRAM + RODS"                         4    "STAPH AUREUS"
  1    "GRAM+ COCCI"                         2    "STAPH EPIDERMIDIS"
  1    "KLEBSIELLA PNEUMONIA"               2    "STAPHYLOCOCCUS"
  1    "LACTOBACILLUS"                       3    "STREP VIRIDANS"
  
```

EVBLDO:  
 1. Required only if EVBLDR=2



**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
 CSSCD INFANT COHORT PATIENTS

EVBLDOC ----- BLOOD CULTURE ORGANISM CODE

type: numeric (float)  
 range: [100,9800] units: 1  
 unique values: 18 coded missing: 7590 / 7656

tabulation:	Freq.	Value
	6	100
	14	105
	4	110
	2	120
	3	130
	2	140
	2	150
	6	170
	2	200
	2	301
	3	401
	2	404
	1	408
	3	800
	5	900
	1	5120
	3	9000
	5	9800

EVBLDOC:

1. Required only if EVBLDR=2
2. See Appendix H for pathogen code list

EVURNS ----- 81B URINE CULTURE DONE

type: numeric (float)  
 label: EVURNS  
 range: [1,2] units: 1  
 unique values: 2 coded missing: 4404 / 7656

tabulation:	Freq.	Numeric	Label
	2470	1	NO
	782	2	YES

EVURNS:

1. Required only if EVVERS='C'

EVURNR ----- 82B URINE CULTURE RESULTS

type: numeric (float)  
 label: EVURNR  
 range: [1,2] units: 1  
 unique values: 2 coded missing: 6884 / 7656

tabulation:	Freq.	Numeric	Label
	717	1	NEGATIVE
	55	2	POSITIVE

EVURNR:

1. Required only if EVURNS=2

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
CSSCD INFANT COHORT PATIENTS

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EVURNO ----- 83B ORGANISM IDENTIFIED IN URINE CULTURE  
                  type: string (str20)

                  unique values: 20                                  coded missing: 0 / 7656

                  tabulation: Freq. Value

5	"."
2	"A"
7597	"C"
1	"BHS - GRP A"
2	"CANDIDA ALBICANS"
1	"CORYNEBACTERIUM"
23	"E COLI"
2	"ENTEROBACTER"
2	"ENTEROBACTER CLOACAE"
2	"ENTEROCOCCUS FAECALI"
1	"GARDNERELLA VAGINALI"
2	"GENITAL FLORA"
1	"GRAM + COCCI"
2	"LACTOBACILLUS"
1	"LACTOSE POS COLIFRMS"
4	"MIXED"
2	"MULTIPLE"
1	"TRICHOMONAS"
1	"UROGENITAL FLORA"
4	"YEAST"

EVURNO:

1. Required only if EVURNR=2

EVURNOC ----- URINE CULTURE ORGANISM CODE  
                  type: numeric (float)

                  range: [105,9800]                                  units: 1  
                  unique values: 8                                  coded missing: 7604 / 7656

                  tabulation: Freq. Value

1	105
1	140
2	203
23	401
4	410
1	900
14	9000
6	9800

EVURNOC:

1. Required only if EVURNR=2
2. See Appendix H for pathogen code list

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
CSSCD INFANT COHORT PATIENTS

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EVTHRS ----- 81C THROAT CULTURE DONE

type: numeric (float)  
label: EVTHRS

range: [1,2] units: 1  
unique values: 2 coded missing: 4407 / 7656

tabulation: Freq. Numeric Label  
2867 1 NO  
382 2 YES

EVTHRS:  
1. Required only if EVVERS='C'

EVTHRR ----- 82C THROAT CULTURE RESULTS

type: numeric (float)  
label: EVTHRR

range: [1,2] units: 1  
unique values: 2 coded missing: 7281 / 7656

tabulation: Freq. Numeric Label  
292 1 NEGATIVE  
83 2 POSITIVE

EVTHRR:  
1. Required only if EVTHRS=2

EVTHRO ----- 83C ORGANISM IDENTIFIED THROAT CULTURE

type: string (str20)

unique values: 11 coded missing: 0 / 7656

tabulation: Freq. Value  
5 "."  
1 "B"  
7570 "C"  
3 "BHS"  
64 "BHS - GRP A"  
6 "BHS - GRP NON-A"  
1 "CANDIDA ALBICANS"  
1 "MIXED"  
1 "S. PNEUMONIAE"  
3 "STAPH - COAG POS"  
1 "STAPH AUREUS"

EVTHRO:  
1. Required only if EVTHRR=2

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
CSSCD INFANT COHORT PATIENTS

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EVTHROC ----- THROAT CULTURE ORGANISM CODE

type: numeric (float)  
range: [105,9800] units: 1  
unique values: 8 coded missing: 7576 / 7656

tabulation:	Freq.	Value
	3	105
	1	110
	64	140
	6	160
	1	170
	3	180
	1	9000
	1	9800

EVTHROC:

1. Required only if EVTHRR=2
2. See Appendix H for pathogen code list

EVOTHS ----- 81D OTHER CULTURE DONE

type: numeric (float)  
label: EVOTHS  
range: [1,2] units: 1  
unique values: 2 coded missing: 4410 / 7656

tabulation:	Freq.	Numeric	Label
	3113	1	NO
	133	2	YES

EVOTHS:

1. Required only if EVVERS='C'

EVOTHR ----- 82D OTHER CULTURE RESULTS

type: numeric (float)  
label: EVOTHR  
range: [1,2] units: 1  
unique values: 2 coded missing: 7530 / 7656

tabulation:	Freq.	Numeric	Label
	77	1	NEGATIVE
	49	2	POSITIVE

EVOTHR:

1. Required only if EVOTHS=2

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
 CSSCD INFANT COHORT PATIENTS

EV0TH0 ----- 83D ORGANISM IDENTIFIED IN OTHER CULTURE

          type: string (str20)  
 unique values: 21                          coded missing: 0 / 7656

tabulation:	Freq.	Value
	4	"."
	7604	"C"
	1	"CANDIDA ALBICANS"
	1	"CHLAMYDIA"
	1	"GARDNERELLA"
	1	"GONOCOCCUS/CHLAMYDIA"
	1	"GONORRHEA"
	3	"GRAM + COCCI"
	9	"MIXED"
	2	"MONONUCLEOSIS"
	1	"MYCOPLASMA PNEUMON."
	2	"NEISSERIA MENINGITID"
	3	"S. PNEUMONIAE"
	1	"SHIGELLA SONNEI"
	1	"STAPH"
	2	"STAPH - COAG NEG"
	1	"STAPH - COAG POS"
	13	"STAPH AUREUS"
	2	"STAPH EPIDERMIDIS"
	1	"TRICHOPHYTON TONSURA"
	2	"YEAST"

EV0TH0:

1. Required only if EV0THR=2

EV0TH0C ----- OTHER CULTURE ORGANISM CODE

          type: numeric (float)  
 range: [105,9800]                          units: 1  
 unique values: 12                          coded missing: 7608 / 7656

tabulation:	Freq.	Value
	6	105
	14	110
	2	120
	3	170
	1	203
	2	301
	1	302
	1	402
	1	5120
	1	5200
	6	9000
	10	9800

EV0TH0C:

1. Required only if EV0THR=2
2. See Appendix H for pathogen code list

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
 CSSCD INFANT COHORT PATIENTS

EVCULTFR ----- 8D1 SOURCE OF OTHER CULTURE SPECIFY  
 type: string (str20)

unique values: 59                      coded missing: 0 / 7656

tabulation:

Freq.	Value	Freq.	Value	Freq.	Value
7	"."	2	"JOINT FLUID"	2	"SKIN"
2	"A"	1	"KNEE ASPIRATE"	35	"SPUTUM"
4	"B"	2	"L HAND WOUND"	1	"SPUTUM&PLEURAL FLUID"
7368	"C"	1	"L. ELBOW FLUID"	18	"STOOL"
61	"BLOOD"	1	"LESION FACE ARM"	2	"STREP SCREEN"
1	"BONE BIOPSY"	1	"LIP"	1	"SURGERY WOUND"
2	"BRONCHIAL"	1	"LUNG"	37	"THROAT"
2	"BRONCHIAL WASH"	2	"MEDIPOINT SITE"	1	"THROAT, EYE"
1	"BRONCHUS"	2	"MONO SPOT"	1	"TIBIA BIOPSY"
1	"CERVICAL"	1	"MYCOPLASMA TITERS"	2	"TIBIAL ABSCESS"
13	"CSF"	1	"NASAL"	1	"TRACH ASPIRATE"
2	"EAR"	1	"NASAL SWAB"	2	"URETHRA"
1	"EAR CULTURE"	1	"NASOPHARYNGEAL"	1	"URETHRAL"
1	"EAR DISCHARGE"	3	"NOSE SWAB"	28	"URINE"
3	"EYE"	2	"NP"	2	"VAGINA"
1	"EYES"	3	"PLEURAL FLUID"	9	"VAGINAL"
1	"FOOT WOUND"	1	"R EAR WOUND"	1	"VAGINAL (CERVICAL)"
2	"FUNGUS"	6	"R FOOT WOUND"	1	"VAGINAL SMEARS"
2	"GENITAL"	1	"RAPID STREP"	1	"WOUND/MEDIPOINT SITE"
1	"GUMS"	1	"SCALP"		

EVCULTFR:

1. Required only if EV0THR=2 or EVCULT=2

EVSER ----- 9 WERE SEROLOGICAL STUDIES PERFORMED  
 type: numeric (float)  
 label: EVSER

range: [1,2]                              units: 1  
 unique values: 2                              coded missing: 4411 / 7656

tabulation:

Freq.	Numeric	Label
3183	1	NO
62	2	YES

EVSER:

1. Required only if EVVERS='C'

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
 CSSCD INFANT COHORT PATIENTS

EVSEARN1 ----- 91A SEROLOGICAL STUDY 1 SPECIFY

**MODIFIED**

type: string (str20)

unique values: 34

coded missing: 0 / 7656

tabulation:

Freq.	Value	Freq.	Value
1	"A"	1	"HEPATITIS A PROFILE"
7593	"C"	2	"HEPATITIS A, B, C"
1	"ANA"	1	"IGG-PARVOVIRUS B-19"
1	"B-HCG"	1	"MONO"
1	"C-REACTIVE PROTEINS"	5	"MYCOPLASMA"
1	"CHLAMYDIA"	1	"MYCOPLASMA ANTIBODY"
3	"COLD AGG SCREEN"	3	"MYCOPLASMA IGG"
1	"COLD AGGLUTININS"	4	"MYCOPLASMA IGM"
1	"EBV"	5	"MYCOPLASMA TITER"
1	"EBV + MONOSPOT"	1	"PARVO B-19 IGG"
1	"G REACTIVE PROTEIN"	7	"PARVOVIRUS"
1	"H. PYLORI AB"	1	"PARVOVIRUS AB"
1	"HAV - IGM"	6	"PARVOVIRUS B-19"
1	"HELICOBACTER"	1	"PARVOVIRUS B19"
2	"HEP A AB IGM"	2	"RPR"
1	"HEP B SURFACE AG"	1	"SYPHILIS"
1	"HEPATIS PROFILE"	2	"VDRL"

EVSEARN1:

- 1. Required only if EVSER=2

EVSEARR1 ----- 92A SEROLOGICAL STUDY 1 RESULTS

type: numeric (float)

label: EVSEARR1

range: [1,2]

units: 1

unique values: 2

coded missing: 7594 / 7656

tabulation:	Freq.	Numeric	Label
	43	1	NEGATIVE
	19	2	POSITIVE

EVSEARR1:

- 1. Required only if EVSER=2

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
 CSSCD INFANT COHORT PATIENTS

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EVSEARN2 ----- 91B SEROLOGICAL STUDY 2 SPECIFY

**MODIFIED**

type: string (str20)

unique values: 19

coded missing: 0 / 7656

tabulation:	Freq.	Value
	2	"A"
	7628	"C"
	1	"ANTI-DNA"
	3	"COLD AGG TITER"
	2	"COOMBS TEST"
	1	"GC"
	1	"HBC - IGM"
	3	"HEP A,B,C"
	1	"HEP B AB"
	1	"HEP B AB - IGM"
	1	"HEP C AB"
	1	"HEP. B"
	1	"HIV + CMV"
	3	"HIV ELISA"
	1	"IGM-PARVOVIRUS B-19"
	1	"MYCOPLASMA"
	3	"MYCOPLASMA IGM"
	1	"PARVO B-19 IGM"
	1	"PARVOVIRUS IGG"

EVSEARN2:

1. Required only if EVSER=2 and >1 serological study performed

EVSEARR2 ----- 92B SEROLOGICAL STUDY 2 RESULTS

type: numeric (float)

label: EVSEARR2

range: [1,2]

units: 1

unique values: 2

coded missing: 7631 / 7656

tabulation:	Freq.	Numeric	Label
	24	1	NEGATIVE
	1	2	POSITIVE

EVSEARR2:

1. Required only if EVSER=2 and >1 serological study performed



**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
 CSSCD INFANT COHORT PATIENTS

EVSENR3 ----- 91C SEROLOGICAL STUDY 3 SPECIFY

**MODIFIED**

```

      type: string (str20)
unique values: 9          coded missing: 0 / 7656
  tabulation: Freq. Value
                2 "A"
              7646 "C"
                1 "CHLAMYDIA ELISA IGG"
                1 "HBSAG"
                1 "HCG"
                1 "HEP B AB"
                1 "HEP C AB"
                1 "HEPATITIS SCREENING"
                2 "HIV"
  
```

EVSENR3:

1. Required only if EVSER=2 and >1 serological study performed

EVSENR3 ----- 92C SEROLOGICAL STUDY 3 RESULTS

```

      type: numeric (float)
      label: EVSENR3
      range: [1,1]          units: 1
unique values: 1          coded missing: 7646 / 7656
  tabulation: Freq. Numeric Label
                10          1 NEGATIVE
  
```

EVSENR3:

1. Required only if EVSER=2 and >1 serological study performed

EVASEVNT ----- 10 OTHER EVNTS ASSOC. W/ THIS EVENT

```

      type: numeric (float)
      label: EVASEVNT
      range: [1,2]          units: 1
unique values: 2          coded missing: 1 / 7656
  tabulation: Freq. Numeric Label
                5561          1 NO
                2094          2 YES
  
```

EVVENT ----- 11 DID PT REQUIRE VENTILATOR SUPPORT

```

      type: numeric (float)
      label: EVVENT
      range: [1,2]          units: 1
unique values: 2          coded missing: 4356 / 7656
  tabulation: Freq. Numeric Label
                3288          1 NO
                12           2 YES
  
```

EVVENT:

1. Required only if EVVERS='C'

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
CSSCD INFANT COHORT PATIENTS

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EVVENTD ----- 111 # OF DAYS PATIENT ON VENTILATOR

type: numeric (float)

range: [2,40]

units: 1

unique values: 5

coded missing: 7645 / 7656

tabulation:	Freq.	Value
	5	2
	2	6
	1	8
	2	30
	1	40

EVVENTD:

1. Required only if EVVENT=2

EVTRANS ----- 12 WAS PT TRANSFUSED FOR THIS EVENT

type: numeric (float)

label: EVTRANS

range: [1,8]

units: 1

unique values: 3

coded missing: 6 / 7656

tabulation:	Freq.	Numeric	Label
	6696	1	NO
	953	2	YES
	1	8	NOT APPLICABLE - EVENT DEATH

EVTRANS:

1. 8 was not a response choice on EVVERS='C'

EVDIE ----- 13 DID PT DIE AS RESULT OF THIS EVENT

type: numeric (float)

label: EVDIE

range: [1,2]

units: 1

unique values: 2

coded missing: 4316 / 7656

tabulation:	Freq.	Numeric	Label
	3338	1	NO
	2	2	YES

EVDIE:

1. Required only if EVVERS='C'

**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
CSSCD INFANT COHORT PATIENTS

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EVNTRNSC ----- DATA TRANSCRIBED FROM OLDER VERSION

type: numeric (float)  
label: EVNTRNSC  
range: [1,2] units: 1  
unique values: 2 coded missing: 4261 / 7656

tabulation:	Freq.	Numeric	Label
	3281	1	NO
	114	2	YES

EVNTRNSC:

1. Required only if EVVERS='C'

EVNOVERS ----- VERSION DATA TRANSCRIBED FROM

type: string (str2)  
unique values: 5 coded missing: 0 / 7656

tabulation:	Freq.	Value
	1	"-1"
	7542	"-7"
	42	"A"
	4	"G"
	67	"H"

EVNOVERS:

1. Required only if EVNTRNSC=2



**CODEBOOK FOR CSSCD FORM NCVA**  
**NON-CVA EVENT FORM - PAGE 2**  
CSSCD INFANT COHORT PATIENTS

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EVORGC ----- ORGANISM CODE (PH2)

type: numeric (float)

range: [100,9800]

units: 1

unique values: 24

coded missing: 7497 / 7656

tabulation:	Freq.	Value
	1	100
	10	110
	3	120
	1	130
	31	140
	1	160
	24	170
	6	180
	2	302
	4	400
	25	401
	3	402
	7	404
	5	408
	2	410
	1	800
	5	1200
	1	1300
	1	3100
	9	5120
	1	6100
	10	9000
	1	9700
	5	9800

EVORGC:

1. Required only if EVCULT=2
2. See Appendix H for pathogen code list

\_dta:

1. Codebook created 02/10/2000