

CSSCD Phases 2 and 3
1.2: Physical Exam – Form PEP

A. Collection Information:

Form PEP (Physical Exam Form) was completed at the entry, annual, and exit visits during both Phase 2 and Phase 3. The physical exam was to be completed at a time when the patient was free of signs and symptoms of an acute event. The following evaluations were performed:

- Measurements of height, weight, blood pressure, distance between tonsils, liver size, and spleen size;
- Examination of extremities for pain and limitation of motion;
- Neurological examination (see Section 1.3)

B. Data Collection Period: 09/89-09/98

Approximately 5 patients completed their last exam between 10/1/98 and 1/15/99.

C. Form Versions: G (08/04/89)

A (09/30/90)

E (10/01/91)

F (03/21/94)

Notes are included in the codebook for questions not included on all form versions. Questions which were on the Physical Exam form used during phase 2 but not Phase 3 are at the end of the codebook.

D. Files Used to Store Information:

SAS System File: **PEP_PUBN.SD2**

Format File: **PEPN.FMT**

E. Unique Record Identifiers: **ANONID, PEPID2**

Records within the dataset are sorted by **ANONID** and **PEPID2**.

F. Number of Observations (Patients) in SAS Dataset: 3112 (467)

G. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 6-7
- Listing of Variables by Position: See pp. 8-9

H. Notes About Selected Variables:

- **PETONSIL, PE_NEURO, PEABNE** – not required if age < 6

I. Computed Variables: None

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J. Inter-Relationship With Other Datasets:

Physical exam data were also collected on

Form Abbreviation	SAS Dataset	See Section
PFIF	PFIFPUBN.SD2	2.11
PFTP	PFTPPUBN.SD2	2.12

COOPERATIVE STUDY OF SICKLE CELL DISEASE

PHYSICAL EXAM

1. Person completing form (Name): _____ **PEFC** (Initials):

2. CSSCD code number of person completing form: _____ **PECODE**

3. Date of physical exam (Month, Day, Year): _____ / _____ / _____ **PE_DATE**

4. HEIGHT (cm): _____ **PEHGT** .

5. WEIGHT (kg): _____ **PEWGT** .

6. BLOOD PRESSURE - SUPINE, BEFORE BLOOD DRAWING OR AT LEAST 15 MINUTES AFTER BLOOD DRAWING
(Sys/Dia) / **PEBPS** **PEBPD**

7. TONSILS - ESTIMATE DISTANCE BETWEEN MEDIAL SURFACES OF TONSILS -OR- CHECK APPROPRIATE BOX BELOW **PETONSIL**
 cm - Kissing - N/A Tonsillectomy - Not Done

8. LIVER - distance below RCM at the MCL (cm) **PELVRS**

9. SPLEEN - distance below LCM at the MCL (cm) **PESPLTP** N/A Splenectomized

10. EXTREMITIES: pain and/or limitation of motion in:
(CHECK NO OR YES FOR 10 A - D)

		1. NO	2. YES
10.A. Right hip	PERHPLM	<input type="checkbox"/>	<input type="checkbox"/>
10.B. Left hip	PELHPLM	<input type="checkbox"/>	<input type="checkbox"/>
10.C. Right shoulder	PERSHLM	<input type="checkbox"/>	<input type="checkbox"/>
10.D. Left shoulder	PELSHLM	<input type="checkbox"/>	<input type="checkbox"/>

11. Was a neurologic exam performed during this visit? 1. NO 2. YES **PE_NEURO**
IF YES TO QUESTION 11, COMPLETE A NEUROLOGICAL EVALUATION FORM

Signature of Data Coordinator: _____ Date: _____ / _____ / _____

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QUESTION-BY-QUESTION SPECIFICATIONS FOR PHYSICAL EXAM FORM

Question 1. Person completing form: The doctor or nurse performing the exam should enter his/her name on the line and his/her 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 doctor or nurse completing the form/performing the exam is to be assigned by the Data Coordinator at each clinic.

Question 3. Date of physical exam: The date the physical exam was performed should be entered in the MM/DD/YY date format (e.g. October 24, 1994 would be entered 10/24/94).

Question 4. Height: Height measurements are to be made with the patient in stocking (bare) feet using a standard wall or scale set. Feet should be together and touching the wall with the patient's arms at his/her side. The chin should be straight and the patient is to be straightened by the examiner. The height measurement should be recorded in centimeters (cm). The formula for conversion from inches to centimeters is as follows: height in inches X 2.54 = height in centimeters. If a patient is unusually short or tall for his/her age, please note this on the form to the left of the height boxes.

Question 5. Weight: Weight measurements are to be made when the patient has no shoes on and most of his/her clothing has been removed. A standard hospital scale should be used. The weight measurement should be recorded in kilograms (kg). The formula for conversion from pounds to kilograms is as follows: weight in pounds/2.2 = weight in kilograms. If the patient is moderately to grossly under- or over-weight for his or her age, please note this on the form to the left of the weight boxes.

Question 6. Blood pressure: Blood pressure measurements are to be made while the patient is supine and has been lying still for at least 5 minutes. The blood pressure should be taken before blood drawing or at least 15 minutes after blood drawing. If the blood pressure is to be done following the blood draw, the blood pressure should be taken on the opposite arm of the blood draw. The patient should not have had a

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cigarette for at least 30 minutes. The blood pressure readings should be recorded in millimeters of mercury (mm Hg).

Proper measurement of blood pressure begins with selection of a cuff of appropriate size. The blood pressure cuff should cover 2/3 of the upper arm and is applied to the arm approximately one inch above the natural crease across the inner aspect of the elbow. The tubing to be connected to the sphygmomanometer should be away from the patient's body, while the tubing to the inflating bulb should be close to the patient's body. Attach the cuff connection to the standard device and inflate the cuff while palpating the radial pulse. The pressure is slowly increased until the patient's pulse is no longer palpable and the mercury reading at which this occurs is noted and will be used to determine the inflation level for all blood pressure readings.

Measuring systolic blood pressure - Systolic blood pressure is determined by inflating the cuff at a smooth continuous rate to 30 mmHg higher than the reading at which the patient's pulse was no longer palpable, and then deflating the cuff at a slow constant rate (approximately 2 mmHg/second) until beats can first be heard with a stethoscope that has been placed over the brachial artery. This is the systolic blood pressure that should be recorded.

Measuring diastolic blood pressure - Diastolic blood pressure is determined by continuing to deflate the blood pressure cuff until there is a dampening of the beats heard, followed by the disappearance of perceptible beats. This latter point is the fifth phase and is the diastolic pressure that should be recorded.

Question 7. Tonsils: The distance between the medial surfaces of the tonsils should be estimated in centimeters and recorded in the appropriate box for question 7. This measurement should be rounded to the nearest whole number (e.g. 3, not 2.5) when appropriate, or a check mark should be made in the box of one of the other three choices (Kissing, N/A .i.e., patient had tonsillectomy, or Not Done). Recording of two values (e.g., 2-3 cm) is an inappropriate response. If the estimated distance is between two whole numbers, the measurement should be rounded to the closest whole number.

Question 8. Liver size: Using a tape measure, project a line down the abdomen from the midclavicular line (MCL) to the lower costal margin on the right (RCM). The liver size

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is to be recorded in centimeters (cm) from this point to the palpated lower margin of the liver while the patient is taking a deep breath. The measured distance should be rounded to the nearest whole number (e.g. if the liver is 1.5 cm below the RCM at the MCL the value should be rounded up to 2 and recorded on the physical exam form as 2).

Question 9. Spleen size: Using a tape measure, measure in centimeters (cm) the spleen at its point of maximal extension below the left costal margin (LCM) at the mid-clavicular line (MCL) while the patient is taking a deep breath. The measured distance should be rounded to the nearest whole number (e.g. if the spleen is palpated at 0.5 cm below the LCM at the MCL, the value should be rounded up to 1 and recorded on the physical exam form as 1). If the patient has been splenectomized, DO NOT record the measurement as 0, instead put a check mark in the box to the left of the words “N/A Splenectomized”.

Question 10. Extremities: The extremities (right & left hips, right and left shoulders) should be assessed for pain as well as range of motion. Evaluate pain and range of motion in each shoulder by passively flexing and extending each arm at the shoulder. Evaluate pain and range of motion in each hip by passively adducting, abducting, flexing and extending each leg at the hip. Place a check in the appropriate NO or YES box next to each extremity being assessed.

Question 11. Was a neurological exam performed during this visit?: Completion of a neurological exam and the Neurological Evaluation Form are required. The neurological evaluation should be completed on the same day as the physical examination for the study visit. Place a check mark in the appropriate NO or YES box for this question. If question 11 is answered YES .i.e., a neurological evaluation was performed at this visit, please be sure to send the completed CSSCD Neurological Evaluation Form to the SCC along with the rest of the study forms for this visit. If a neurological evaluation was not performed, please write in the reason on the Physical Exam form.

If developmental delay, hearing, vision, speech, and/or other neurological problems are identified, the appropriate clinical referral(s) should be made.

CODEBOOK FOR CSSCD FORM PEP
PHYSICAL EXAM FORM
 CSSCD INFANT COHORT PATIENTS

CONTENTS OF SAS DATASET: PEP_PUBN.SD2
 DATA FROM CSSCD FORM PEP - PHYSICAL EXAM
 VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
 IN THE SAS DATASET AND ON FORM PEP
 DATE VARIABLES HAVE BEEN REMOVED & CSSCD ID #S REPLACED W/ ANONYMIZED ID #

The SAS System 14:00 Friday, February 13, 2004 2

The CONTENTS Procedure

Data Set Name: IN.PEP_PUBN	Observations:	3112
Member Type: DATA	Variables:	25
Engine: V6	Indexes:	0
Created: 14:07 Friday, February 13, 2004	Observation Length:	187
Last Modified: 14:07 Friday, February 13, 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:	36
First Data Page:	1
Max Obs per Page:	87
Obs in First Data Page:	69
Number of Data Set Repairs:	0
File Name:	pep_pubn.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			
25	PEABNE	Num	8	179	2.	2.	ABNORMAL NEUROLOGICAL EXAM (PH 2)
4	PEBNO	Num	8	17	3.	3.	DATA ENTRY BATCH NUMBER
8	PEBPD	Num	8	49	3.	3.	6B DIASTOLIC BLOOD PRESSURE-DIASTOLIC
7	PEBPS	Num	8	41	3.	3.	6A SYSTOLIC BLOOD PRESSURE-SUPINE
24	PEEXLM	Char	8	171			LOCATION OF PAIN/LIMITATION (PH 2)
5	PEHGT	Num	8	25	5.1	5.1	4 HEIGHT
2	PEID2	Num	8	8	3.	3.	FOLLOW-UP IDENTIFIER
22	PELANLM	Num	8	155	2.	2.	PAIN/MOTION LIMITATION IN L ANKLE (PH 2)
13	PELHPLM	Num	8	89	2.	2.	10B PAIN/MOTION LIMITATION IN L HIP
20	PELKNLM	Num	8	139	2.	2.	PAIN/MOTION LIMITATION IN L KNEE (PH 2)
15	PELSHLM	Num	8	105	2.	2.	10D PAIN/MOTION LIMITATION IN L
SHOULDER							
10	PELVRSZ	Num	8	65	2.	2.	8 LIVER - DIST BELOW RCM AT MCL (CM)
23	PEOTHLM	Num	8	163	2.	2.	OTHER SITE OF PAIN/LIMITATION (PH 2)
18	PEOVERS	Char	2	129			VERSION DATA TRANSCRIBED FROM
21	PERANLM	Num	8	147	2.	2.	PAIN/MOTION LIMITATION IN R ANKLE (PH 2)
12	PERHPLM	Num	8	81	2.	2.	10A PAIN/LIMITATION OF MOTION IN R HIP
19	PERKNLM	Num	8	131	2.	2.	PAIN/MOTION LIMITATION IN R KNEE (PH 2)
14	PERSHLM	Num	8	97	2.	2.	10C PAIN/MOTION LIMITATION IN R SHOULDER
11	PESPLTP	Num	8	73	2.	2.	9 SPLEEN - DIST BELOW LCM AT MCL (CM)
9	PETONSIL	Num	8	57	2.	2.	7 DIST BETW MEDIAL SURFACES OF TONSILS
17	PETRNSC	Num	8	121	2.	2.	DATA TRANSCRIBED FROM OLDER VERSION
3	PEVERS	Char	1	16			FORM VERSION

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6	PEWGT	Num	8	33	5.1	5.1	5 WEIGHT
16	PE_NEURO	Num	8	113	2.	2.	11 NEUROLOGICAL EXAM PERFORMED

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

PROC FORMAT;

```
VALUE ID2F 1='1-PH2 ENTRY VIS'
           3='3-PH2 ANN 1 VIS'
           5='5-PH2 ANN 2 VIS'
           7='7-PH2 ANN 3 VIS'
           9='9-PH2 ANN 4 VIS'
           11='11-PH3 ENTRY VIS'
           13='13-PH3 ANN 1 VIS'
           15='15-PH3 ANN 2 VIS'
           17='17-PH3 ANN 3 VIS'
           19='19-PH3 ANN 4 VIS';
```

```
* Format NO_YES used for the following variables: PERHPLM PELHPLM
  PERSHLM PELSHLM PE_NEURO PETRNSC PERKNLM PELKNLM PERANLM
  PELANLM PEOTHLM PEABNE;
```

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

```
format PEID2 ID2F.
       PERHPLM PELHPLM PERSHLM PELSHLM PE_NEURO PETRNSC PERKNLM
       PELKNLM PERANLM PELANLM PEOTHLM PEABNE NO_YES.;
```

```
run;
quit;
```


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PEID2 ----- FOLLOW-UP IDENTIFIER

type: numeric (float)
 label: PEID2

range: [1,19] units: 1
 unique values: 12 coded missing: 0 / 3112

tabulation:	Freq.	Numeric	Label
	467	1	1-PH2 ENTRY VIS
	421	3	3-PH2 ANN 1 VIS
	394	5	5-PH2 ANN 2 VIS
	378	7	7-PH2 ANN 3 VIS
	141	9	9-PH2 ANN 4 VIS
	378	11	11-PH3 ENTRY VIS
	1	12	
	323	13	13-PH3 ANN 1 VIS
	2	14	
	293	15	15-PH3 ANN 2 VIS
	297	17	17-PH3 ANN 3 VIS
	17	19	19-PH3 ANN 4 VIS

PEVERS ----- FORM VERSION

type: string (str1)

unique values: 4 coded missing: 0 / 3112

tabulation:	Freq.	Value
	422	"A"
	903	"E"
	1312	"F"
	475	"G"

PEHGT ----- 4 HEIGHT

type: numeric (float)

range: [76.2,193] units: .1
 unique values: 660 coded missing: 61 / 3112

mean: 135.83
 std. dev: 19.6865

percentiles: 10% 25% 50% 75% 90%
 110 122.3 136 150 162

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CSSCD INFANT COHORT PATIENTS

PEWGT ----- 5 WEIGHT

type: numeric (float)

range: [7.6,118.2] units: .1
unique values: 586 coded missing: 18 / 3112

mean: 33.7461
std. dev: 15.0626

percentiles:	10%	25%	50%	75%	90%
	18.1	22.8	30	41.1	54.9

PEBPS ----- 6A SYSTOLIC BLOOD PRESSURE-SUPINE

type: numeric (float)

range: [70,160] units: 1
unique values: 65 coded missing: 1847 / 3112

mean: 109.508
std. dev: 11.3218

percentiles:	10%	25%	50%	75%	90%
	96	100	110	118	123

PEBPS:

1. Response required only if PEVERS=F.

PEBPD ----- 6B DIASTOLIC BLOOD PRESSURE-DIASTOLIC

type: numeric (float)

range: [30,94] units: 1
unique values: 53 coded missing: 1848 / 3112

mean: 60.6812
std. dev: 9.48076

percentiles:	10%	25%	50%	75%	90%
	50	54	60	68	72

PEBPD:

1. Response required only if PEVERS=F.

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PETONSIL ----- 7 DIST BETW MEDIAL SURFACES OF TONSILS

type: numeric (float)

range: [0,10]

units: 1

unique values: 10

coded missing: 982 / 3112

tabulation: Freq. Value

86	0
441	1
964	2
392	3
195	4
43	5
6	6
1	7
1	8
1	10

PETONSIL:

1. Response required only if PEVERS=A, E, or F.

PELVRSZ ----- 8 LIVER - DIST BELOW RCM AT MCL (CM)

type: numeric (float)

range: [0,14]

units: 1

unique values: 11

coded missing: 59 / 3112

tabulation: Freq. Value

2311	0
312	1
244	2
110	3
32	4
22	5
11	6
6	7
2	9
2	10
1	14

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PESPLTP ----- 9 SPLEEN - DIST BELOW LCM AT MCL (CM)

type: numeric (float)

range: [0,8]

units: 1

unique values: 9

coded missing: 167 / 3112

tabulation:	Freq.	Value
	2661	0
	85	1
	78	2
	50	3
	29	4
	18	5
	19	6
	4	7
	1	8

PERHPLM ----- 10A PAIN/LIMITATION OF MOTION IN R HIP

type: numeric (float)

label: PERHPLM

range: [1,2]

units: 1

unique values: 2

coded missing: 2 / 3112

tabulation:	Freq.	Numeric	Label
	3066	1	NO
	44	2	YES

PELHPLM ----- 10B PAIN/MOTION LIMITATION IN L HIP

type: numeric (float)

label: PELHPLM

range: [1,2]

units: 1

unique values: 2

coded missing: 3 / 3112

tabulation:	Freq.	Numeric	Label
	3073	1	NO
	36	2	YES

PERSHLM ----- 10C PAIN/MOTION LIMITATION IN R SHOULDER

type: numeric (float)

label: PERSHLM

range: [1,2]

units: 1

unique values: 2

coded missing: 2 / 3112

tabulation:	Freq.	Numeric	Label
	3090	1	NO
	20	2	YES

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PELSHLM ----- 10D PAIN/MOTION LIMITATION IN L SHOULDER

type: numeric (float)
 label: PELSHLM

range: [1,2] units: 1
 unique values: 2 coded missing: 3 / 3112

tabulation:	Freq.	Numeric	Label
	3096	1	NO
	13	2	YES

PE_NEURO ----- 11 NEUROLOGICAL EXAM PERFORMED

type: numeric (float)
 label: PE_NEURO

range: [1,2] units: 1
 unique values: 2 coded missing: 1814 / 3112

tabulation:	Freq.	Numeric	Label
	129	1	NO
	1169	2	YES

PE_NEURO:

1. Response required only if PEVERS=F.
2. See PEABNE.

PETRNSC ----- DATA TRANSCRIBED FROM OLDER VERSION

type: numeric (float)
 label: PETRNSC

range: [1,2] units: 1
 unique values: 2 coded missing: 1800 / 3112

tabulation:	Freq.	Numeric	Label
	1291	1	NO
	21	2	YES

PEOVERS ----- VERSION DATA TRANSCRIBED FROM

type: string (str2)

unique values: 3 coded missing: 0 / 3112

tabulation:	Freq.	Value
	3091	"-7"
	1	"A"
	20	"E"

PEOVERS:

1. Response required only if PETRNSC=2.

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PERKNLM ----- PAIN/MOTION LIMITATION IN R KNEE (PH 2)

type: numeric (float)
label: PERKNLM

range: [1,2] units: 1
unique values: 2 coded missing: 1312 / 3112

tabulation:	Freq.	Numeric	Label
	1776	1	NO
	24	2	YES

PERKNLM:

1. Response required only if PEVERS=A, E, or G.

PELKNLM ----- PAIN/MOTION LIMITATION IN L KNEE (PH 2)

type: numeric (float)
label: PELKNLM

range: [1,2] units: 1
unique values: 2 coded missing: 1312 / 3112

tabulation:	Freq.	Numeric	Label
	1789	1	NO
	11	2	YES

PELKNLM:

1. Response required only if PEVERS=A, E, or G.

PERANLM ----- PAIN/MOTION LIMITATION IN R ANKLE (PH 2)

type: numeric (float)
label: PERANLM

range: [1,2] units: 1
unique values: 2 coded missing: 1313 / 3112

tabulation:	Freq.	Numeric	Label
	1790	1	NO
	9	2	YES

PERANLM:

1. Response required only if PEVERS=A, E, or G.

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PELANLM ----- PAIN/MOTION LIMITATION IN L ANKLE (PH 2)

type: numeric (float)

label: PELANLM

range: [1,2]

units: 1

unique values: 2

coded missing: 1313 / 3112

tabulation:	Freq.	Numeric	Label
	1796	1	NO
	3	2	YES

PELANLM:

1. Response required only if PEVERS=A, E, or G.

PEOTHLM ----- OTHER SITE OF PAIN/LIMITATION (PH 2)

type: numeric (float)

label: PEOTHLM

range: [1,2]

units: 1

unique values: 2

coded missing: 1317 / 3112

tabulation:	Freq.	Numeric	Label
	1758	1	NO
	37	2	YES

PEOTHLM:

1. Response required only if PEVERS=A, E, or G.

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PEEXLM ----- LOCATION OF PAIN/LIMITATION (PH 2)
 type: string (str8)

unique values: 35 coded missing: 1312 / 3112

tabulation:

Freq.	Value	Freq.	Value
1763	"-7"	1	"LOM 2DG"
1	"ABD PAIN"	1	"LOW BACK"
1	"ABDOMEN"	1	"LOWER BK"
1	"BIL.FEET"	1	"LW BK BI"
1	"BOTH_ARM"	1	"PAIN LEG"
1	"CHEST/HA"	1	"R ARM HD"
1	"COCCYX"	1	"R ELBOW"
1	"FINGER"	1	"R FACE"
1	"L ARM"	1	"R FOOT"
2	"L ELBOW"	1	"R HEMI"
2	"L LEG"	1	"R THIGH"
1	"L WRIST"	1	"R. HAND"
1	"L WRST P"	1	"R.FA/HND"
1	"L. HAND"	1	"RARPAIN"
1	"L.ELBOW"	2	"RFARM+HD"
1	"LEFT ARM"	1	"STERNUM"
1	"LEYEDROP"	1	"THROAT"
1	"LIMP RLG"		

PEEXLM:

1. Response required only if PEVERS=A, E, or G.
2. Response required only if PEOTHLM=2.

PEABNE ----- ABNORMAL NEUROLOGICAL EXAM (PH 2)

type: numeric (float)
 label: PEABNE

range: [1,3] units: 1
 unique values: 3 coded missing: 1529 / 3112

tabulation:	Freq.	Numeric	Label
	1443	1	NO
	136	2	YES
	4	3	

PEABNE:

1. Response required only if PEVERS=A, E, or G.
2. Also see PE_NEURO.

_dta:

1. Created 01/19/00.