

PUBLIC USE DATASET

ANNOTATED eCRF

Critical Pertussis in U.S. Children

Severe Morbidity, Sequelae, and Mortality:
A Prospective Cohort Study

CPCCRN Protocol Number 001

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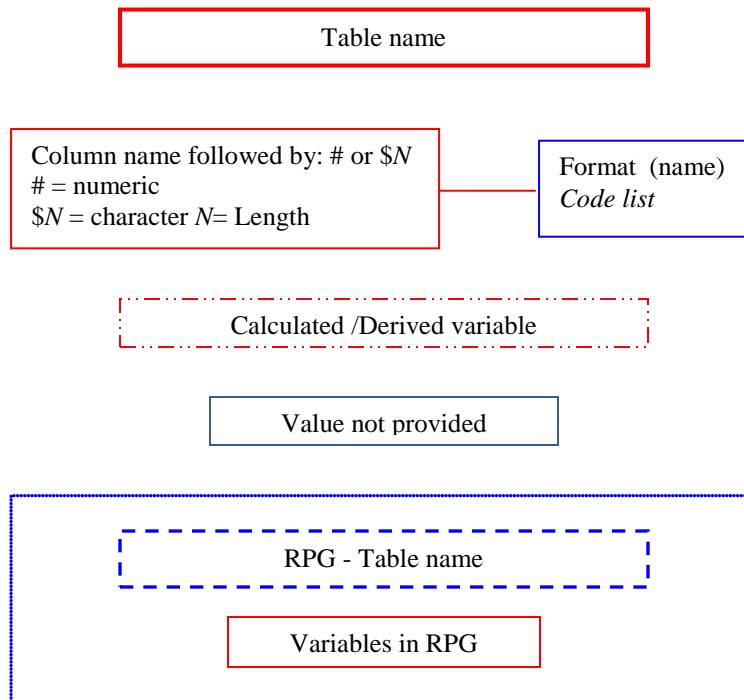
Annotated eCRF Version 1.0

PUD Version Date: November 24, 2015

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Annotations key



Notes

SubjectID is a randomly generated ID that is unique for each subject enrolled in the study. SubjectID is present in all datasets to facilitate merging. Some forms have multiple records for a subject. The unique identifier(s) for each form are provided just below the dataset name.

All out-of-range and other questionable data have been included in the public use datasets.

Sensitive and/or identifying information entered in free text fields have been removed from the public use datasets.

Demographics (1 of 1)

SubjectID

Demographics

*Patient ID	SubjectID #	
*DOB (MM/DD/YYYY)	Value not provided	
*Sex	SEX \$1	
*Race	RACE #	<div style="border: 1px solid blue; padding: 5px; width: fit-content;"> DV403G 1 = American Indian or Alaska Native 2 = Asian 3 = Black or African American 4 = Native Hawaiian or Other Pacific Islander 5 = White 6 = Unknown 7 = Other </div>
Ethnicity	HISPANIC_ETHNICITY #	<div style="border: 1px solid blue; padding: 5px; width: fit-content;"> DV6484G -1 = Hispanic or Latino 0 = Not Hispanic or Latino 1 = Unknown </div>

Race Other	OTHER_RACE \$50
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Derived variables included in the Demographics dataset:

Variable	Format	Type	Label	Algorithm / Notes
ageindays		#	Patient age at PICU admission (days)	
ageinmonths		#	Patient age at PICU admission (months)	
ageinyears		#	Patient age at PICU admission (years)	Rounded to 2 decimal places.

Eligibility (1 of 1)

SubjectID

Eligibility and Consent

DV2425G

1 = Spent at least 24 consecutive hours in PICU
2 = Spent any time in the PICU and died in the unit

Case Definition Specifics

Date of admission to PICU?

PICUAdmitDay #

Time of admission to PICU?

PICUAdmitTime \$4

Critical nature of illness

LengthHospStay #

Type of eligibility

EligibilityType #

Vital status when eligibility was determined

VitalStatus #

DV1512G

1 = Alive
2 = Deceased

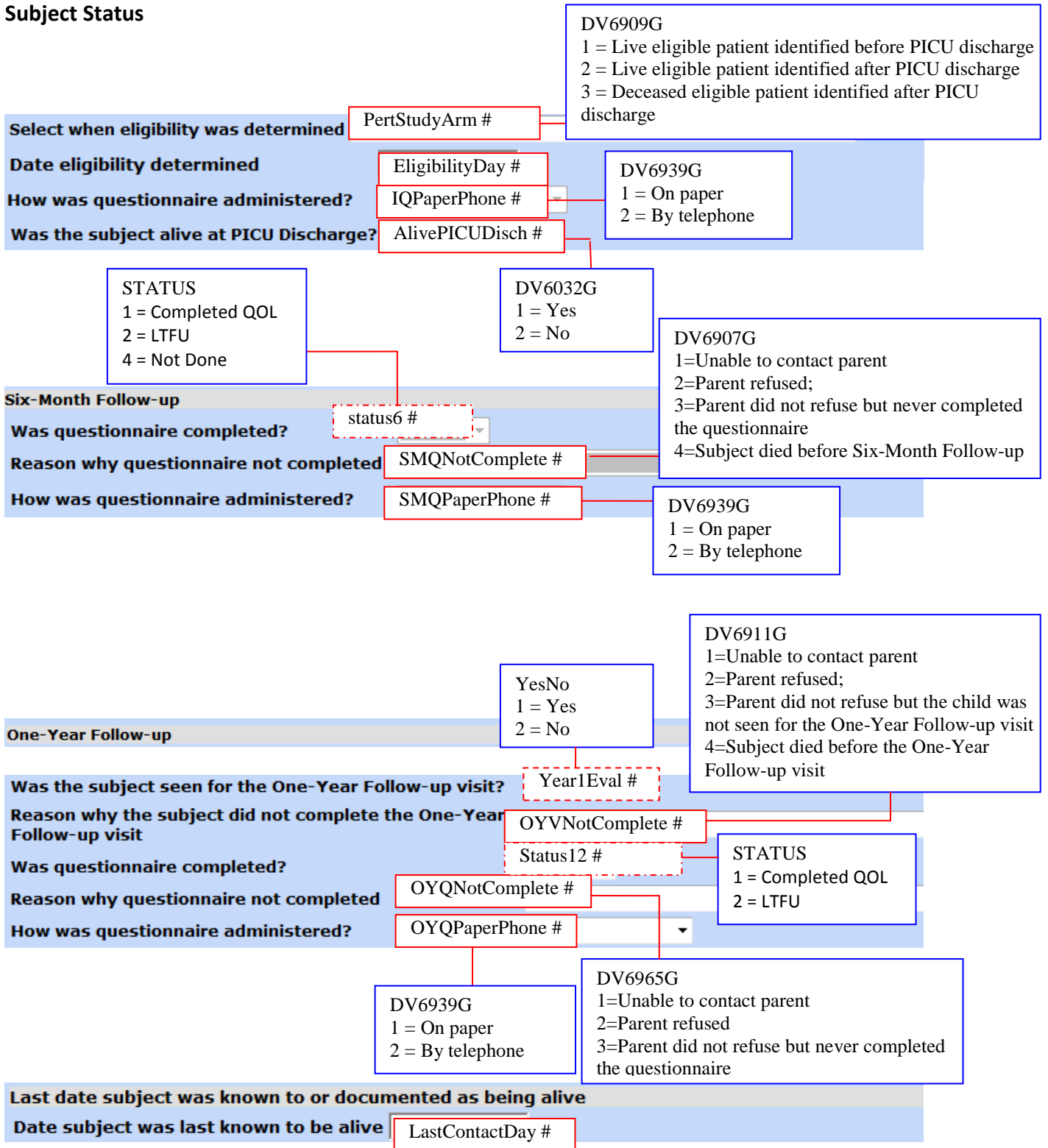
DV2966G

1 = Positive culture with or without a positive PCR test
2 = Type 2 - positive PCR
3 = Type 3 - epidemiologic link
4 = Type 4 - post-mortem evidence
5 = Type 5 - clinical syndrome

SubjectStatus (1 of 2)

SubjectID

Subject Status



SubjectStatus (2 of 2)

Derived variables included in the SubjectStatus dataset:

Variable	Format	Type	Label	Algorithm / Notes
elig6	YESNO 1 = Yes 0 = No	#	Eligible for 6 month follow-up	Subject is eligible for six month follow up if s/he did not die or withdraw from the study prior to 6 months.
status6	STATUS 1 = Completed QOL 2 = LTFU 4 = Not Done	#	Month 6 follow-up status	LTFU = Lost to follow up. A subject may only be considered LTFU at six months if s/he is ineligible for one year follow up.
elig12	YESNO 1 = Yes 0 = No	#	Eligible for 12 month follow-up	Subject is eligible for twelve month follow up if s/he < 1 year old at the time of PICU admission and did not die or withdraw from the study prior to 12 months.
status12	STATUS 1 = Completed QOL 2 = LTFU	#	Month 12 follow-up status	LTFU = Lost to follow up.
year1eval	YESNO 1 = Yes 0 = No	#	On-site evaluation completed (12 month)	
year1Mullen	YESNO 1 = Yes 0 = No	#	Mullen completed (12 month)	

ITQOL (1 of 4)

SubjectID

TimePoint

ITQOL – Infant & Toddler QOL Questionnaire

Section 1: Your Child's Health Overall

Date

Is your child at least 1 year of age or older?

In general, how would you rate your child's health?

QuestionnaireDay #

ITQOLAge #

ITQOL11 #

DV445G

1 = No
2 = Yes

DV62G

1 = Excellent
2 = Very good
3 = Good
4 = Fair
5 = Poor
6 = Not answered

Section 2: Your Child's Physical Abilities

Considering your child's age and abilities, has he/she been limited in any of the following because of health or learning problems?

Feeding/nursing/eating

ITQOL21a #

Sleeping

ITQOL21b #

Grasping

ITQOL21c #

Reaching

ITQOL21d #

Rolling over

ITQOL21e #

Sitting up

ITQOL21f #

Crawling

ITQOL21g #

Playing

ITQOL21h #

Taking steps or walking

ITQOL21i #

Running

ITQOL21j #

DV493G

1 = Yes, limited a lot
2 = Yes, limited some
3 = Yes, limited a little
4 = No, not limited
5 = Not doing yet
6 = Not answered

Section 3: Satisfaction With Your Child's Overall Growth and Development

In general, how satisfied are you with your child's:

Physical growth and development?

ITQOL31a #

Motor development?

ITQOL31b #

Responsiveness to others?

ITQOL31c #

Language development?

ITQOL31d #

Learning abilities or cognitive development?

ITQOL31e #

Feeding/nursing/eating habits?

ITQOL31f #

Sleep habits?

ITQOL31g #

Bowel habits?

ITQOL31h #

General temperament?

ITQOL31i #

Overall growth and development?

ITQOL31j #

DV494G

1 = Very satisfied
2 = Somewhat satisfied
3 = Neither satisfied nor dissatisfied
4 = Somewhat dissatisfied
5 = Very dissatisfied
6 = Not answered

ITQOL (2 of 4)

Section 4: Your Child's Discomfort/Pain

During the past 4 weeks:

How much bodily pain or discomfort has your child had?

ITQOL41 #

How often has your child had discomfort or pain?

ITQOL42 #

How much did discomfort or pain interfere with his/her usual activities?

ITQOL43 #

DV346G
 1 = None
 2 = Mild
 3 = Moderate
 4 = Severe
 5 = Very severe
 6 = Not answered

DV347G
 1 = None of the time
 2 = A few times
 3 = Fairly often
 4 = Very often
 5 = Every day/almost every day
 6 = Not answered

DV495G
 1 = None at all
 2 = A little bit
 3 = Some
 4 = Quite a bit
 5 = A lot
 6 = Not answered

Section 5: Your Child's Temperament and Moods

During the past 4 weeks, how much time did your child seem:

To have trouble sleeping?

ITQOL51a #

To be a picky feeder/nurser/eater?

ITQOL51b #

Cranky, fussy, or irritable?

ITQOL51c #

Less active than usual?

ITQOL51d #

Happy?

ITQOL51e #

Difficult to comfort?

ITQOL51f #

Interested in activities going on around him/her?

ITQOL51g #

More quiet than usual?

ITQOL51h #

Bothered or upset?

DV551G
 1 = All of the time
 2 = Most of the time
 3 = Some of the time
 4 = A little of the time
 5 = None of the time
 6 = Not answered

ITQOL51i #

"Just not him/herself"?

ITQOL51j #

Responsive to others?

ITQOL51k #

Cheerful?

ITQOL51l #

Easily upset?

ITQOL51m #

Fearful of others?

ITQOL51n #

Playful?

ITQOL51o #

Alert?

ITQOL51p #

To want to be held more often or seem more clingy than usual?

ITQOL51q #

To do well with changes in his/her routine?

ITQOL51r #

Section 6: Your Child's Behavior Overall

How much do you agree/disagree with each statement for your child?

My child's behavior is excellent.	ITQOL61a #
My child's behavior is sometimes difficult to manage.	ITQOL61b #
My child seems to misbehave quite often.	ITQOL61c #
My child seems to misbehave more often than other children I know.	ITQOL61d #
My child's behavior is rarely very bad.	ITQOL61e #
I think my child's behavior will be worse in the future.	ITQOL61f #
I rarely worry about my child's behavior.	ITQOL61g #
Doctors or other child professionals have suggested that my child's behavior is a problem.	ITQOL61h #
I think my child's behavior will not be a problem for him/her in the future.	ITQOL61i #
People have complimented me on my child's behavior.	ITQOL61j #
I worry about my child's behavior more than other parents worry about their child's behavior.	ITQOL61k #
Others have complained about my child's behavior.	ITQOL61l #
Compared to children of the same age, how would you rate your child's behavior overall?	ITQOL62 #

DV6028G
 1 = Strongly agree
 2 = Agree
 3 = Not sure
 4 = Disagree
 5 = Strongly disagree
 6 = Not answered

DV62G
 1 = Excellent
 2 = Very good
 3 = Good
 4 = Fair
 5 = Poor
 6 = Not answered

Section 7: Getting Along With Others

During the past 4 weeks, how often did your child:

Seem to cooperate with others?	ITQOL71a #
Seem unable to sit still for more than a few minutes?	ITQOL71b #
Go to sleep or to bed with few problems?	ITQOL71c #
Hit, kick, or bite others?	ITQOL71d #
Appear sorry after having misbehaved?	ITQOL71e #
Have behavior that was difficult to manage?	ITQOL71f #
Seem able to adjust to new situations or strangers?	ITQOL71g #
Act shy or timid?	ITQOL71h #
Get along with other children?	ITQOL71i #
Throw tantrums?	ITQOL71j #
Respond positively to affection?	ITQOL71k #
Act withdrawn?	ITQOL71l #
Seem distracted more than other children his/her age?	ITQOL71m #
Act his/her age?	ITQOL71n #
Listen or follow directions?	ITQOL71o #

DV496G
 1 = Very often
 2 = Fairly often
 3 = Sometimes
 4 = Almost never
 5 = Never
 6 = Not answered

Section 8: Your Child's Health

How true or false is each statement for your child?

- My child's health is excellent.
- My child was once so sick, I thought he/she might die.
- My child seems to resist illness very well.
- My child seems to be less healthy than other children I know.
- My child has never been seriously ill.
- When there is something going around my child usually catches it.
- I think my child's health will be worse in the future than it is now.
- I expect my child will have a very healthy life.
- I rarely worry about my child's health.
- Doctors say my child is healthy now.
- I worry about my child's health more than other people worry about their children's health.
- Compared to one year ago, how would you rate your child's health now:

DV497G
 1 = Definitely true
 2 = Mostly true
 3 = Not sure
 4 = Mostly false
 5 = Definitely false
 6 = Not answered

ITQOL81a #

ITQOL81b #

ITQOL81c #

ITQOL81d #

ITQOL81e #

ITQOL81f #

ITQOL81g #

ITQOL81h #

ITQOL81i #

ITQOL81j #

ITQOL81k #

ITQOL82 #

DV501G
 1 = Much better now than 1 year ago
 2 = Somewhat better now than 1 year ago
 3 = About the same now as 1 year ago
 4 = Somewhat worse now than 1 year ago
 5 = Much worse now than 1 year ago
 6 = Not answered

Section 9: Your Child's Impact On You

During the past 4 weeks, how MUCH anxiety or worry did each of the following cause YOU?

- Your child's feeding/eating/sleeping habits
- Your child's physical health
- Your child's emotional well-being
- Your child's learning abilities or cognitive development
- Your child's ability to interact with others
- Your child's behavior
- Your child's temperament

ITQOL91a #

ITQOL91b #

ITQOL91c #

ITQOL91d #

ITQOL91e #

ITQOL91f #

ITQOL91g #

DV495G
 1 = None at all
 2 = A little bit
 3 = Some
 4 = Quite a bit
 5 = A lot
 6 = Not answered

During the past 4 weeks, were you LIMITED in the amount of time YOU had for your own personal needs due to problems with your child's:

- Feeding/eating/sleeping habits
- Physical health
- Emotional well-being
- Learning abilities or cognitive development
- Ability to interact with others
- Behavior
- Temperament

DV498G
 1 = Yes, limited a lot
 2 = Yes, limited some
 3 = Yes, limited a little
 4 = No, not limited
 5 = Not answered

ITQOL92a #

ITQOL92b #

ITQOL92c #

ITQOL92d #

ITQOL92e #

ITQOL92f #

ITQOL92g #

ITQOL93 #

DV62G
 1 = Excellent
 2 = Very good
 3 = Good
 4 = Fair
 5 = Poor
 6 = Not answered

In general, how would you rate your family's ability to get along with one another?

Derived variables included in the ITQOL dataset:

Variable	Format	Type	Label	Algorithm / Notes
timepoint	TimePt 1 = Baseline 2 = Six months 3 = One year	#	Time point of questionnaire	
OHraw		#	Overall Health (raw)	See note 1.
OH		#	Overall Health (0-100)	See note 2.
PA2raw		#	Physical Abilities (raw)	See note 1.
PA2		#	Physical Abilities (0-100)	See note 2.
GDraw		#	Growth and Development (raw)	See note 1.
GD		#	Growth and Development (0-100)	See note 2.
BPrAw		#	Bodily Pain/Discomfort (raw)	See note 1.
BP		#	Bodily Pain/Discomfort (0-100)	See note 2.
TMraw		#	Temperament and Moods (raw)	See note 1.
TM		#	Temperament and Moods (0-100)	See note 2.
GBraw		#	General Behavior (raw)	See note 1.
GB		#	General Behavior (0-100)	See note 2.
GB2raw		#	Global Behavior Item (raw)	See note 1.
GB2		#	Global Behavior Item (0-100)	See note 2.
BEraw		#	Behavior - Getting Along with Others (raw)	See note 1.
BE		#	Behavior - Getting Along with Others (0-100)	See note 2.
GHraw		#	General Health Perceptions (raw)	See note 1.
GH		#	General Health Perceptions (0-100)	See note 2.
CH		#	Change in Health (categorical)	This item should remain as a categorical variable and does not need to be transformed.
PEraw		#	Parental Impact - Emotional (raw)	See note 1.
PE		#	Parental Impact - Emotional (0-100)	See note 2.
PTraw		#	Parental Impact - Time (raw)	See note 1.
PT		#	Parental Impact - Time (0-100)	See note 2.
FCraw		#	Family Cohesion (raw)	See note 1.
FC		#	Family Cohesion (0-100)	See note 2.

Note 1: Based on published instructions for calculating raw scores for the ITQOL-97. The manual used for scoring was: Infant and Toddler Quality of Life Questionnaire-97 (ITQOL-97) Confidential Scoring Instructions (2007). Boston, MA: HealthActCHQ, Inc. These instructions are confidential and cannot be shared directly with this study documentation.

Note 2: Based on published instructions for calculating transformed scores for the ITQOL-97 (see reference above). The transformed scores for all scales range from 0 to 100, with higher scores indicating better health.

CHQ (1 of 2)

SubjectID

TimePoint

CHQ – Child Health Questionnaire

Section 1: Your Child's Global Health	
Date	QuestionnaireDay #
In general, would you say your child's health is:	CHQ11 #
Section 2: Your Child's Physical Activities	
During the past 4 weeks, has your child been limited in any of the following activities due to health problems?	
Doing things that take a lot of energy?	CHQ21a #
Doing things that take some energy?	CHQ21b #
Bending, lifting or stooping?	CHQ21c #
Section 3: Your Child's Everyday Activities	
During the past 4 weeks, has your child been limited in the:	
AMOUNT of time he/she could spend on activities due to EMOTIONAL or BEHAVIORAL problems?	CHQ31 #
KIND of activities he/she could do due to problems with his/her PHYSICAL HEALTH?	CHQ32 #
Section 4: Pain	
During the past 4 weeks, how often has your child had bodily pain or discomfort?	CHQ41 #
Section 5: Behavior	
How often during the past 4 weeks did each of the following statements describe your child?	
Argued a lot?	CHQ51a #
Had difficulty concentrating or paying attention?	CHQ51b #
Lied or cheated?	CHQ51c #
In general, would you say his/her behavior is:	CHQ52 #
Section 6: Well-Being	
During the past 4 weeks, how much of the time do you think your child:	
Felt lonely?	CHQ61a #
Acted nervous?	CHQ61b #
Acted bothered or upset?	CHQ61c #
Section 7: Self-Esteem	
During the past 4 weeks, how satisfied do you think your child has felt about:	
His/her school ability?	CHQ71a #
His/her friendships?	CHQ71b #
His/her life overall?	CHQ71c #

DV62G
1 = Excellent
2 = Very good
3 = Good
4 = Fair
5 = Poor
6 = Not answered

DV498G
1 = Yes, limited a lot
2 = Yes, limited some
3 = Yes, limited a little
4 = No, not limited
5 = Not answered

CHQ31 #
CHQ32 #

DV499G
1 = None of the time
2 = Once or twice
3 = A few times
4 = Fairly often
5 = Very often
6 = Every/almost every day
7 = Not answered

DV496G
1 = Very often
2 = Fairly often
3 = Sometimes
4 = Almost never
5 = Never
6 = Not answered

DV62G
1 = Excellent
2 = Very good
3 = Good
4 = Fair
5 = Poor
6 = Not answered

DV551G
1 = All of the time
2 = Most of the time
3 = Some of the time
4 = A little of the time
5 = None of the time
6 = Not answered

DV494G
1 = Very satisfied
2 = Somewhat satisfied
3 = Neither satisfied nor dissatisfied
4 = Somewhat dissatisfied
5 = Very dissatisfied
6 = Not answered

CHQ (2 of 2)

Section 8: Your Child's Health

How true or false is each of these statements for your child?

My child seems to be less healthy than other children I know.

My child has never been seriously ill.

I worry more about my child's health than other people worry about their children's health.

Compared to one year ago, how would you rate your child's health now:

- DV500G
- 1 = Definitely true
 - 2 = Mostly true
 - 3 = Don't know
 - 4 = Mostly false
 - 5 = Definitely false
 - 6 = Not answered

- CHQ81a #
- CHQ81b #
- CHQ81c #
- CHQ82 #

Section 9: You and Your Family

During the past 4 weeks, how MUCH emotional worry or concern did each of the following cause YOU?

Your child's physical health

Your child's emotional well-being or behavior

- DV501G
- 1 = Much better now than 1 year ago
 - 2 = Somewhat better now than 1 year ago
 - 3 = About the same now as 1 year ago
 - 4 = Somewhat worse now than 1 year ago
 - 5 = Much worse now than 1 year ago
 - 6 = Not answered

- CHQ91a #
- CHQ91b #

- DV495G
- 1 = None at all
 - 2 = A little bit
 - 3 = Some
 - 4 = Quite a bit
 - 5 = A lot
 - 6 = Not answered

During the past 4 weeks, were you LIMITED in the amount of time YOU had for your own needs because of:

Your child's physical health

Your child's emotional well-being or behavior

- DV498G
- 1 = Yes, limited a lot
 - 2 = Yes, limited some
 - 3 = Yes, limited a little
 - 4 = No, not limited
 - 5 = Not answered

- CHQ92a #
- CHQ92b #

During the past 4 weeks, how often has your child's health or behavior:

Limited the types of activities you could do as a family?

Interrupted various everyday family activities?

In general, how would you rate your family's ability to get along with one another?

- DV496G
- 1 = Very often
 - 2 = Fairly often
 - 3 = Sometimes
 - 4 = Almost never
 - 5 = Never
 - 6 = Not answered

- DV62G
- 1 = Excellent
 - 2 = Very good
 - 3 = Good
 - 4 = Fair
 - 5 = Poor
 - 6 = Not answered

- CHQ93a #
- CHQ93b #
- CHQ94 #

Derived variables included in the CHQ dataset:

Variable	Format	Type	Label	Algorithm / Notes
timepoint	TimePt 1 = Baseline 2 = Six months	#	Time point of questionnaire	
GGHraw		#	Global Health (raw)	See note 1.
GGH		#	Global Health (0-100)	See note 2.
PFRaw		#	Physical Functioning (raw)	See note 1.
PF		#	Physical Functioning (0-100)	See note 2.
REBraw		#	Role/Social Limitations - Emotional/Behavioral (raw)	See note 1.
REB		#	Role/Social Limitations - Emotional/Behavioral (0-100)	See note 2.
RPRaw		#	Role/Social Limitations - Physical (raw)	See note 1.
RP		#	Role/Social Limitations - Physical (0-100)	See note 2.
BPRaw		#	Bodily Pain/Discomfort (raw)	See note 1.
BP		#	Bodily Pain/Discomfort (0-100)	See note 2.
BERaw		#	Behavior (raw)	See note 1.
BE		#	Behavior (0-100)	See note 2.
GBERaw		#	Global Behavior Item (raw)	See note 1.
GBE		#	Global Behavior Item (0-100)	See note 2.
MHraw		#	Mental Health (raw)	See note 1.
MH		#	Mental Health (0-100)	See note 2.
SEraw		#	Self Esteem (raw)	See note 1.
SE		#	Self Esteem (0-100)	See note 2.
GHraw		#	General Health Perceptions (raw)	See note 1.
GH		#	General Health Perceptions (0-100)	See note 2.
CH		#	Change in Health (categorical)	This item should remain as a categorical variable and does not need to be transformed.
PERaw		#	Parental Impact - Emotional (raw)	See note 1.
PE		#	Parental Impact - Emotional (0-100)	See note 2.
PTraw		#	Parental Impact - Time (raw)	See note 1.
PT		#	Parental Impact - Time (0-100)	See note 2.
FARaw		#	Family Activities (raw)	See note 1.
FA		#	Family Activities (0-100)	See note 2.

FCraw		#	Family Cohesion (raw)	See note 1.
FC		#	Family Cohesion (0-100)	See note 2.

Note 1: Based on published instructions for calculating raw scores for the CHQ-PF28. The manual used for scoring was: Child Health Questionnaire (CHQ) Scoring and Interpretation Manual (2008). Boston, MA: HealthActCHQ, Inc. These instructions are confidential and cannot be shared directly with this study documentation.

Note 2: Based on published instructions for calculating transformed scores for the CHQ-PF28 (see reference above). The transformed scores for all scales range from 0 to 100, with higher scores indicating better health.

SubjectInfo (1 of 2)

SubjectID

Subject and Birth Information

Date of Interview

Date of interview InterviewDay #

Subject Information

Method of Interview

DV3G
1 = In person
2 = By telephone

Birth place of subject

MethodInterview #

BirthCountry #

DV96G

1 = United States
2 = Mexico
3 = Central America other than Mexico
4 = Caribbean
5 = South America
6 = Europe
7 = Africa
8 = Asia
9 = Australia
10 = Pacific Islands
11 = Other

Other birth place

BirthCountryOth \$5

Relationship of person being interviewed, to subject

RelationInterview #

Other relationship

OtherRelation1 \$5

Race of biological mother

RaceBioMother #

Other race of mother

OthRaceMother \$50

Ethnicity of biological mother

EthnBioMother #

Relationship of primary caregiver, to subject

RelationPCG #

Other relationship

OtherRelation2 \$5

Race of primary caregiver

RacePCG #

Other race of primary caregiver

OtherRacePCG \$50

Ethnicity of primary caregiver

EthnPCG #

Is the age of the primary caregiver known?

AgePCGKnown #

Age of primary caregiver

AgePCG #

Highest education of primary caregiver

EducationPCG, #

Work situation of primary caregiver

WorkSitPCG #

DV100G

1 = Mother biological
2 = Father biological
3 = Mother by adoption or stepmother
4 = Father by adoption or stepmother
5 = Grandmother
6 = Grandfather
7 = Other relative
8 = Guardian or foster parent
9 = Babysitter, nanny, governess
10 = Other

DV6539G
1 = Hispanic or Latino
2 = Not Hispanic or Latino
3 = Would not state
4 = Unknown

DV6459G
1 = American Indian or Alaska Native
2 = Asian
3 = Black or African American
4 = Islander
5 = White
6 = Stated as unknown
7 = Other

DV618G

1 = Known
2 = Unknown

DV393G

1 = Working or attending school >= 30 hours per week
2 = Working or attending school < 30 hours per week
3 = Full time care giver of subject, not looking for work
4 = Looking for work
5 = Unknown

DV386G

1 = Some high school or less
2 = High school diploma or GED
3 = Vocational school or some college
4 = College degree
5 = Graduate or doctoral degree
6 = Unknown

SubjectInfo (2 of 2)

Birth Information

Subject born premature (< 37 weeks gestation)

DV2741G
1 = Yes
2 = No
3 = Unknown

BornPremature #

Is the gestational age at birth known?

DV618G
1 = Known
2 = Unknown

GestAgeKnown #

Gestational age at birth (weeks)

GestAgeBirth #

Is the birth weight known?

BirthWeightKnow #

Birth weight unit of measurement

DV559G
1 = Pounds
2 = Kilograms

BirthWeightUnit #

Birth weight (lb)

BirthWeightLb #

Birth weight (oz)

BirthWeightOz #

Birth weight (kg)

BirthWeightKg #

Multiple births?

MultipleBirths #

Medical complications for the baby during pregnancy, labor, or delivery

MedCompBaby #

List complications

ListCompBaby \$255

Subject required special medical care due to problems during pregnancy, labor, or delivery

SpecialMedCare #

List special medical care

ListMedCare \$255

Is the age of the subject at discharge after birth known?

DV618G
1 = Known
2 = Unknown

DischAgeKnown #

Subject age at discharge after birth (days)

DischAge #

Is the age of the biological mother at birth of subject known?

AgeBioMotherKn #

Biological mother's age at birth of subject (years)

AgeBioMother #

DV394G
1 = No, single birth
2 = Yes, twins
3 = Yes, triplets
4 = Yes, more than triplets
5 = Unknown

DV395G
1 = No complications
2 = Unknown if there were complications
3 = Yes, but they did not require hospitalization
4 = Yes, and they required hospitalization of baby

DV397G
1 = No special medical care was required
2 = Unknown if special medical care required
3 = Yes, special medical care was required temporarily
4 = Yes, and special medical care continues to be required

Problems with the baby during pregnancy

Problems with the baby during pregnancy	Other problem
BabyProblems #	OtherProblem1 \$100

DV331G
1 = Poor fetal movement
2 = Growth retardation
3 = Other problem
4 = Unknown

BabyProblems
SubjectID
Repeat_Instance

Problems with the baby during pregnancy and/or labor

Were there any problems with the baby during pregnancy?

BabyProblemYN #

Did a healthcare provider diagnose any congenital abnormalities (birth defects)?

CongenAbnormal #

Did the baby have to stay in the neonatal intensive care unit (NICU) before discharge home?

NICUStay #

If the baby was in the NICU, was mechanical ventilation (breathing machine) required?

MechVentReq #

DV398G
1 = Yes
2 = No
3 = Unsure

PertIllness (1 of 3)

SubjectID

Pertussis Illness Information

Date of interview			
Date of interview	InterviewDay #		DV398G 1 = Yes 2 = No 3 = Unsure
Immunization History			
Did the child ever receive a pertussis (whooping cough) vaccine?		PertussisVacc #	
Is the number of doses received known?		NumDosesKnown #	DV618G 1 = Known 2 = Unknown
How many doses were received?	DV183G 1 = < 3 months of age 2 = >= 3 months of age	NumberDoses #	
Chronological age of child		ChronoAgeChild #	
What was the reported shot status for subject?		ShotStatus #	
Onset of Acute Pertussis			
Is the date known when the child became ill or appeared less well than usual?		DV618G 1 = Known 2 = Unknown	IllnessStartKn #
When did the child become ill or appear less well than usual? (Date)			IllnessStartDay #
If date not known, estimated number of days the child was ill before the PICU admission? (Number of days)			EstDaysIllness #
Baseline neurodevelopmental status			
Did the child seem behind, compared with other infants or children of the same age?	DV184G 1 = The subject has received all shots on time 2 = The subject has missed some shots 3 = The interviewee does not know about the subject's shot history	DV6901G 1 = Normal 2 = Abnormal 3 = Indeterminate 4 = Not done	DV398G 1 = Yes 2 = No 3 = Unsure
What were the results of the newborn hearing screening test?			CompareInfants #
Was the caregiver told by a healthcare provider that the child had developmental delay?			HearingTest #
Was the caregiver told by a healthcare provider that the child had vision problems?			DevelopDelay #
Was the caregiver told by a healthcare provider that the child had hearing problems?			VisionProblems #
Was the child receiving early intervention for developmental delay, vision problems or hearing problems?			HearingProblems #
			EarlyIntervent #

PertIllness (2 of 3)

Subject Health Status Before Pertussis Illness

Indicate if the parents were told by a healthcare provider that the subject had any of the following conditions prior to onset of pertussis.

Asthma or reactive airway disease	HSAsthmaOrRAD #	<div style="border: 1px solid blue; padding: 5px;"> DV398G 1 = Yes 2 = No 3 = Unsure </div>
Chronic lung disease other than asthma	HSCLDNotAsthma #	
Heart disease, congenital or acquired	HSHrtDiseaseCOA #	
Metabolic or hormone disease, such as diabetes	HSHormDisease #	
Suppressed immune system	HSSupprImmune #	
Allergy	HSAllergy #	
Blood or hemoglobin disease	HSBloodDisease #	
Kidney disease	HSKidneyDisease #	
Gastrointestinal disease, such as reflux	HSGIDisease #	
Epilepsy or seizures	HSEpilepsy #	
Receiving anticonvulsants	HSAnticonvulsan #	
Other neurologic or neuromuscular disorder	HSNeuroDisorder #	
Genetic anomaly or congenital malformation	HSGeneAnomaly #	
Cancer	HSCancer #	
Trauma requiring hospitalization	CondReqHospital #	

Before the pertussis illness, did the subject have any of the following medical devices?

Gastrostomy tube	DeviceGT #	<div style="border: 1px solid blue; padding: 5px;"> DV398G 1 = Yes 2 = No 3 = Unsure </div>
Other feeding tube	DeviceOFT #	
Tracheostomy	DeviceTrach #	
Home ventilator	DeviceHV #	
Ventricular shunt (CSF)	DeviceVSCSF #	

PertIllness (3 of 3)

History of Pertussis Illness

Did the child have a cough during the acute pertussis illness?

CoughDurIllness #

DV2741G
1 = Yes
2 = No
3 = Unknown

Is the date when the cough started known?

CoughStartKn #

DV618G
1 = Known
2 = Unknown

What date did the cough start?

CoughStartDay

If date unknown, how many days prior to PICU admission?

DaysPriorAdmit #

When did the cough stop?

CoughStop #

DV14G
1 = Still coughing at time of PICU admission
2 = Cough stopped on specific date
3 = Cough stopped, but timing uncertain
4 = Unsure if cough has stopped

Specific date cough stopped

CoughStopDay #

Was cough associated with any of the following symptoms before coming to the

Couldn't stop coughing or hard to catch breath

UnableStopCough #

High pitched noise (whoop) between spells

WhoopSpells #

Vomiting after the coughing

VomitCough #

Fainting or passing out during or after coughing spell

FaintingCough #

Did the child have any of the following other symptoms during the acute pertussis illness, prior to admission to the PICU?

Stopped breathing for 20 sec or longer, unassociated with cough

StopBreathing #

Tongue or face turned blue, unassociated with cough

TongueFaceBlue #

Runny nose or nasal congestion

NasalCongest #

Fever above 101 degrees F

FeverMore101F #

Difficulty with feeding

DifficultFeed #

Seizures or convulsions

SeizureOrConvul #

DV398G
1 = Yes
2 = No
3 = Unsure

InPICUCA (1 of 2)

SubjectID

Initial PICU Chart Abstraction

Birth History Data				
Is the birth weight known?	BirthWeightKnow #	DV618G		
Birth weight (kg)	BirthWeightKg #	DV618G		
Is the gestational age at birth known?	GestAgeKnown #	DV618G		
Gestational age at birth	GestAgeAtBirth #	DV2741G		
Was the subject admitted to the NICU?	PNICUAdmission #	DV2741G		
NICU mechanical ventilation or CPAP?	HxNICUMechVent #	DV2741G		
Immunization				
Are there any documented pertussis vaccinations?	PertSourceYN #	DV6032G		

Immunization Status	ImmuneStatus	SubjectID	Repeat_instance
Scheduled dose	Source of information	Other source of information	
ChronoAge #	SourceOfInfo #	OtherSource \$50	
DV6686G 1 = 2 months (as early as 6 wks) 2 = 4 months 3 = 6 months 4 = 15-18 months 5 = 4-6 years 6 = 11-12 years 7 = Unknown	DV1886G 1 = Regular primary care providers office/clinic 2 = Public health clinic 3 = Hospital records, including emergency department 4 = Urgent care records 5 = Immunization registry; 6 = Parent record (immunization card) 7 = Other 8 = Unknown		
Date of Administration	Type of vaccine	Specify other type of vaccine	Type of DTap vaccine
AdministrationDay #	VaccineType #	OthVaccineType \$25	VaccineTypeDTap #
	DV2279G 1 = DTap 2 = DTP 3 = DTP/DTap 4 = DT 5 = Tdap 6 = Td 7 = None 8 = Unknown 9 = Other		DV565G 1 = DTap alone, 2 = DTap-Hib 3 = DTap-HepB-IPV 4 = DTap-Hib-IPV 5 = Other
			VaccineName \$50

InPICUCA (2 of 2)

Symptoms present at time of admission

Cough	Cough #	DV6032G 1 = Yes 2 = No
Cyanosis	ASCyanosis #	
Apnea	apnea #	
Bradycardia	ASBradycardia #	
Respiratory Distress	ASRespDistress #	
Seizures	ASSeizures #	
Altered mental status	ASAltMentStat #	

Admission vital signs

Is the length/height documented?	VSHeightCMDoc #	DV6032G 1 = Yes 2 = No
Length/Height (cm)	VSHeightCM #	
Length/Height percentile for age	VSHeightP #	
Is the weight documented?	VSWeightCMDoc #	DV6032G 1 = Yes 2 = No
Weight (kg)	VSWeightKG #	
Weight percentile for age	VSWeightP #	DV6032G 1 = Yes 2 = No
Is the head circumference documented?	VSHeadCircCMDoc #	DV6032G 1 = Yes 2 = No
Head circumference (cm)	VSHeadCircCM #	
Head circumference percentile for age	VSHeadCircP #	
Temperature (Celsius)	VSTempCelsius #	
Respiratory rate	VSRespRate #	
Heart rate	VSHeartRate #	
Oxygen saturation % (first reading in PICU)	VSOxygenSatP #	
FiO2 at time of oxygen saturation measurement (%)	VSVFiO2 #	

Neurological Findings

Neurological findings (age wnl, altered tone/posturing/movements) NeuroFindings #

Status on Admission to PICU

Muscle relaxant	ASMuscleRelax #	DV6032G 1 = Yes 2 = No	DV4229G 1 = Grossly normal for age 2 = Altered tone, posturing, or abnormal movements 3 = Unable to asses because of heavy sedation or muscle relaxant
Intubated	ASIntubated #		
Mechanical ventilation	ASMechVent #		
PICU admission diagnosis	ASPICUAdmitDx \$255		

Notes

Out of range percentiles in the Fenton Growth Chart are typically source reported as "< 3" or ">97". Due to the entry restriction of integer fields (i.e. VSHeadCircP, VSWeightP and VSHeightP), study sites were instructed to enter "2" for percentiles reported as "<3" and "98" for percentiles reported as "> 97".

Likewise, Standard Growth Chart percentiles reported as "< 5" are recorded as "4" and percentiles reported as ">95" are recorded as "96".

Derived variables included in the InPICUCA dataset:

Variable	Format	Type	Label	Algorithm / Notes
PRISMIIICalcS		#	PRISM III Score	Based on the first 12 hours of PICU admission.

PertLab

SubjectID

Repeat_instance

Pertussis Laboratory Data

Pertussis Laboratory Data			
Type of test	Other type of test	Date of collection	Time of collection
TypeLabTest3 #	OthTypeLabTest \$25	CollectionDay #	CollectionTime \$4
DV329G 1 = Culture 2 = PCR 3 = Serology 4 = Direct fluorescent antibody (DFA) 5 = Other			
Laboratory facility	Other laboratory facility	Specimen type	
LabFacility #	LabFacilityOth \$5	PertSpecimenTyp #	
DV1336G 1 = Hospital laboratory 2 = Commercial laboratory 3 = Public health department 4 = CDC 5 = Other		DV4445G 1 = Nasopharyngeal (NP) swab 2 = Nasopharyngeal (NP) dry aspirate 3 = Nasopharyngeal (NP) wash 4 = Nasopharyngeal (NP) – unspecified 5 = Blood 6 = Lung biopsy 7 = Fiberoptic bronchoalveolar lavage (BAL) 8 = Deep alveolar lavage 9 = Endotracheal suctioning 10 = Post-mortem specimens 11 = Other 12 = Unknown	
DV1599G 1 = Positive 2 = Negative 3 = Equivocal			
Specify other specimen type or post-mortem specimens		Result of test	
PertSpecTypeOth \$50		ResultLabTest3 #	

PastMedHx (1 of 1)

SubjectID

Documented Past Medical History

Documented Past Medical History	
Asthma or reactive airway disease	HxAsthma #
Chronic lung disease other than asthma	HxLungDisease #
Heart disease, congenital or acquired	HxHeartDisease #
Metabolic or hormone disease, such as diabetes	HxMetabolicDis #
Suppressed immune system	HxSuppImmune #
Allergy	HxAllergy #
Blood or hemoglobin disease	HxBloodDisease #
Kidney disease	HxKidnDisease #
Gastrointestinal disease, such as reflux	HxGIDisease #
Chronic epilepsy or seizures	HxEpilepsy #
Seizures associated with current illness	HxSeizureCurIll #
Receiving anticonvulsants	HxReceivingAnti #
Other neurologic or neuromuscular disorder	HxOthNeuro #
Genetic anomaly or congenital malformation	HxGeneAnomaly #
Cancer	HxCancer #
Trauma requiring hospitalization	HxTraumaHosp #

DV546G
1 = Yes
2 = No
3 = Not documented

DailyData (1 of 3)

SubjectID

ProtocolStudyDay

Daily PICU Data Collection (Days 0 -28)

Study Date	
Study Date	StudyDay #
Neurological Parameters	
Neuromuscular blockade (any time during the day)	NPNeuroBlock #
Receiving anticonvulsants	NPRecAnticonv #
Seizure	NPSeizure #
Abnormal posturing	NPAbnormPosture #
Evidence of CNS bleed	NPEvidCNSBleed #
Altered mental status	ASAltMentStat #
Other abnormal neurological observation noted	NPOtherAbnorm #
<div data-bbox="1247 621 1409 726" style="border: 1px solid black; padding: 5px;"> DV6032G 1 = Yes 2 = No </div>	
Respiratory Parameters	
Cough	RPCough #
Cyanosis	ASCyanosis #
Apnea	Apnea #
Chest x-ray (for Day 0, include chest x-rays done prior to PICU admission)	ChestXray #
Nasal cannula	RPNasalCannula #
Nasal CPAP	RPNasalCPAP #
Other non-invasive ventilatory support	RPOthVentSupp #
Conventional mechanical ventilation	RPConvMechVent #
High frequency ventilation	RPHighFreqVent #
ECMO or ECLS	RPECMOorECLS #
Inhaled Nitric Oxide	RPInhaleNtrcOxd #
<div data-bbox="1117 877 1328 1016" style="border: 1px solid black; padding: 5px;"> DV440G 1 = Yes 2 = No 3 = Intubated </div>	
<div data-bbox="1117 1024 1328 1163" style="border: 1px solid black; padding: 5px;"> DV6899G 1 = Normal 2 = Abnormal 3 = Not done </div>	
<div data-bbox="1149 1243 1328 1348" style="border: 1px solid black; padding: 5px;"> DV6032G 1 = Yes 2 = No </div>	

DailyData (2 of 3)

Cardiovascular Parameters	
Evidence of cardiac failure	CPEvidCardFail #
Poor Perfusion	CPPoorPerfusion #
Arrhythmia	CPArrhythmia #
Bradycardia	ASBradycardia #
Hypotension	CPHypotension #
Use of vasoactive drips	CPVasoactive #
Pulmonary Hypertension	CPPulmonHypert #
Renal Parameters	
Were Renal Parameters obtained?	RenalParameters #
Creatinine (worst value of day) (mg/dL)	RPCreatinine #
Renal replacement therapy	RPRenalReplace #
Bacterial and Fungal Microbiology Testing	
Were any bacterial and fungal microbiology tests done?	BFMTestingDone #

DV6032G
1 = Yes
2 = No

DV6032G
1 = Yes
2 = No

DV471G
1 = Testing Not Done
2 = Testing Done

Bacterial and Fungal Microbiology		BactFungMic	SubjectID	Repeat_Instance
Type of test	Specify other sterile site culture	Date of test result		
TypeLabTest2 #	SpecifyOthSite \$150	BFMResultDay #		
Result of test		If positive, specify results		
ResultLabTest2 #	PositiveResults \$150			

DV545G
1 = Endotracheal tube culture
2 = Tracheal gram stain
3 = Broncho-alveolar lavage
4 = Blood culture
5 = CSF culture
6 = Urine culture
7 = Other sterile site culture

DV6690G
1 = Negative
2 = Positive
3 = Unknown or inconclusive result

DailyData (3 of 3)

Immunologic/Hematologic Parameters

Were hematology labs recorded on this day?

WBCCollected #

DV6032G

1 = Yes
2 = No

DV6032G

1 = Yes
2 = No

Hematology

SubjectID

Repeat_Instance

Date of collection	Time of collection	Was a differential obtained?	WBC (x10 ³ /uL)	Platelets (x10 ³ /uL)	ALC (x10 ³ /uL)	ANC (x10 ³ /uL)	APC (x10 ³ /uL)
HemLabDay #	HemLabTime \$4	HemLabDiffYN #	HemLabWBC #	HemLabPlatelet #	HemLabALC #	HemLabANC #	HemLabAPC #

Exchange transfusion or leukophoresis

ExchTransLeuko #

RBC transfusion

RBCTransfusion #

Abnormal bleeding

AbnormalBleed #

Use of antibiotics

UseAntibiotics #

DV6032G

1 = Yes
2 = No

Complications Noted During Study Day

Cardiac Arrest

CNCardiacArrest #

Respiratory arrest

CNRespArrest #

Development of pneumonia (new)

CNDevelopPneum #

Pneumothorax

CNPneumothorax #

Death

CNDeath #

Were there other complications noted during this study day?

CNOtherCompl #

Other complications

CNOtherComplText \$255

DV6032G

1 = Yes
2 = No

Derived variables included in the DailyData dataset:

Variable	Format	Type	Label	Algorithm / Notes
ProtocolStudyDay	ProtocolDay 0 = Day 0 1 = Day 1 etc.	#	Protocol-Defined Study Day	See pg. 43 of protocol for definition.

PICU Discharge Information

Discharge Information		
Date of PICU discharge	PICUDCDay #	
Time of PICU discharge (HHMM):	PICUDCTime \$4	
Is the head circumference documented?	VSHeadCircCMDoc #	DV6032G 1 = Yes 2 = No
Head circumference (cm)	VSHeadCircCM #	
Head circumference percentile for age	VSHeadCircP #	
Is the weight documented?	VSWeightCMDoc #	DV6032G 1 = Yes 2 = No
Weight (kg)	VSWeightKG #	
Weight percentile for age	VSWeightP #	
Is the length/height documented?	VSHeightCMDoc #	DV6032G 1 = Yes 2 = No
Length/Height (cm)	VSHeightCM #	
Length/Height percentile for age	VSHeightP #	DV6032G 1 = Yes 2 = No
Receiving anticonvulsants	NPRecAnticonv #	DV6032G 1 = Yes 2 = No
Seizure assessment	SeizureAssess #	
Feeding assessment	FeedingAssess #	
Arousal assessment	ArousalAssess #	
Communication assessment	CommunicAssess #	
Motor strength assessment	MotorAssess #	
Motor tone assessment	MotorToneAssess #	

DV4228G
1 = No seizures occurred during the PICU admission
2 = Seizures documented during PICU admission

DV539G
1 = Oral feeding only
2 = Oral plus tube feeding (NG, NJ, or gastrostomy)
3 = NG or NJ tube feeding only
4 = Gastrostomy feeding only
5 = No enteral feeding

DV542G
1 = Awake, alert, or looks to clapping
2 = Arouses but does not localize sound
3 = Responds to pain with agitation or withdrawal
4 = Non-responsive

DV6902G
1 = Normal tone for age
2 = Increased or decreased tone for age
3 = Moderately floppy or spastic, including poor head control for age
4 = No response to stimulation, severe diffuse spasticity, posturing

DV548G
1 = Normal activity for age
2 = Asymmetric limb activity or withdrawal to stimulation
3 = Withdraws from pain
4 = No response to stimulation

DV547G
1 = Age-appropriate vocalization, facial expressiveness, gestures
2 = Slightly decreased vocalization or non-verbal interaction
3 = Moderately decreased vocalization or non-verbal interaction
4 = No reactivity to speech, gestures, or touch

Notes

Out of range percentiles in the Fenton Growth Chart are typically source reported as "< 3" or ">97". Due to the entry restriction of integer fields (i.e. VSHeadCircP, VSWeightP and VSHeightP), study sites were instructed to enter "2" for percentiles reported as "<3" and "98" for percentiles reported as "> 97".

Likewise, Standard Growth Chart percentiles reported as "< 5" are recorded as "4" and percentiles reported as ">95" are recorded as "96".

OneYear (1 of 1)

SubjectID

One-Year Follow-up

One-Year Follow-Up

Date of follow-up visit

FollowUpVisitDay #

Parent perception of status at time of follow-up

FollowUpStatus2 #

Head circumference (cm)

VSHeadCircCM #

Head circumference percentile for age

VSHeadCircP #

Weight (kg)

VSWeightKG #

Weight percentile for age

VSWeightP #

Length/Height (cm)

VSHeightCM #

Length/Height percentile for age

VSHeightP #

Seizure assessment

SeizureAssess2 #

Feeding assessment

FeedingAssess #

Arousal assessment

ArousalAssess #

Communication assessment

CommunicAssess #

Motor strength assessment

MotorAssess #

Motor tone assessment

MotorToneAssess #

Formal hearing assessment (describe)

HearAssess \$100

Parent's assessment of vision, "Does your child have any problems with vision?"

VisionAssess #

DV4906G
1 = Alive with apparently intact neurodevelopment
2 = Alive with apparent neurodevelopment impairment
3 = Alive but unable to assess neurodevelopment
4 = Deceased

DV6903G
1 = Normal
2 = Abnormal
3 = Parent can't tell

DV330G
1 = No seizures have ever occurred since PICU discharge
2 = Seizures have occurred since PICU discharge but the child is not on anticonvulsants
3 = Seizures have occurred since PICU discharge and the child is on anticonvulsants

DV539 (FeedingAssess)
1 = Oral feeding only
2 = Oral plus tube feeding (NG, NJ, or gastrostomy)
3 = NG or NJ tube feeding only
4 = Gastrostomy feeding only
5 = No enteral feeds

DV542G
1 = Awake, alert, or looks to clapping
2 = Arouses but does not localize sound
3 = Responds to pain with agitation or withdrawal
4 = Non-responsive

DV6902G
1 = Normal tone for age
2 = Increased or decreased tone for age
3 = Moderately floppy or spastic, including poor head control for age
4 = No response to stimulation, severe diffuse spasticity, posturing

DV548G
1 = Normal activity for age
2 = Asymmetric limb activity or withdrawal to stimulation
3 = Withdraws from pain
4 = No response to stimulation

DV547G
1 = Age-appropriate vocalization, facial expressiveness, gestures
2 = Slightly decreased vocalization or non-verbal interaction
3 = Moderately decreased vocalization or non-verbal
4 = No reactivity to speech, gestures, or touch

Notes

Out of range percentiles in the Fenton Growth Chart are typically source reported as "< 3" or ">97". Due to the entry restriction of integer fields (i.e. VSHeadCircP, VSWeightP and VSHeightP), study sites were instructed to enter "2" for percentiles reported as "<3" and "98" for percentiles reported as "> 97".

Likewise, Standard Growth Chart percentiles reported as "< 5" are recorded as "4" and percentiles reported as ">95" are recorded as "96".

Mullen (1 of 1)

SubjectID

Mullen Assessment

Language of Mullen Administration

What language was the Mullen administered?

Other, specify:

If the Mullen was administered in a language other than English, how was it administered?

Other, specify:

DV7193G

1 = English

2 = Spanish

3 = Other

MullenLanguage #

LanguageOther \$50

NonEnglish #

NonEnglishOther \$10

DV7194G

1 = Bilingual examiner

2 = English examiner

with an interpreter

3 = Other

Derived variables included in the Mullen dataset:

Variable	Format	Type	Label	Algorithm / Notes
MullenDay		#	Mullen assessment day (relative to PICU admission)	
ageMullyears		#	Age (years) at Mullen assessment	Rounded to 2 decimal places.
ageMullenmonths		#	Age (months) at Mullen assessment	
ageMullendays		#	Age (days) at Mullen assessment	
GM_RAW		#	Gross Motor Raw Score	See note 1.
VR_RAW		#	Visual Reception Raw Score	See note 1.
FM_RAW		#	Fine Motor Raw Score	See note 1.
RL_RAW		#	Receptive Language Raw Score	See note 1.
EL_RAW		#	Expressive Language Raw Score	See note 1.
GM_TSCR		#	Gross Motor T-Score	See note 2.
VR_TSCR		#	Visual Reception T-Score	See note 2.
FM_TSCR		#	Fine Motor T-Score	See note 2.
RL_TSCR		#	Receptive Language T-Score	See note 2.
EL_TSCR		#	Expressive Language T-Score	See note 2.
COM_SSCR		#	Early Learning Composite Standard Score	See note 3.
COM_PERC		#	Early Learning Composite Percentile Rank	See note 3.

Note 1: Raw scores for the Mullen were calculated at clinical sites following administration (see Mullen, EM (1995). Mullen Scales of Early Learning: AGS Edition Item Administration Book & Manual. Minneapolis, MN: Pearson).

Note 2: Scale T-scores were calculated in Mullen software based on raw scores and child's age. T-scores are standardized to have a mean of 50 and standard deviation of 10 in a normative population (see manual).

Note 3: The Early Learning Composite Standard Score and Percentile Rank were calculated in Mullen software. This score is derived from the four cognitive scales (fine motor, visual reception, receptive language, and expressive language) and is standardized to have a mean of 100 and a standard deviation of 15 in a normative population (see manual).

MullenADJ (1 of 1)

SubjectID

Mullen Assessment (Adjusted)

Language of Mullen Administration

What language was the Mullen administered?

Other, specify:

If the Mullen was administered in a language other than English, how was it administered?

Other, specify:

DV7193G

- 1 = English
- 2 = Spanish
- 3 = Other

MullenLanguage #

LanguageOther \$50

NonEnglish #

NonEnglishOther \$10

DV7194G

- 1 = Bilingual examiner
- 2 = English examiner with an interpreter
- 3 = Other

Derived variables included in the MullenADJ dataset:

Variable	Format	Type	Label	Algorithm / Notes
MullenDay		#	Mullen assessment day (relative to PICU admission)	
ageMullyears		#	Age (years) at Mullen assessment	Rounded to 2 decimal places.
ageMullenmonths		#	Age (months) at Mullen assessment	
ageMullendays		#	Age (days) at Mullen assessment	
Premature	YESNO 1 = Yes 0 = No	#	Born premature	Based on parent report or chart abstraction.
GestAgeBirthWks		#	Gestational age at birth in weeks	Based on parent report, or, if unavailable, chart abstraction.
GM_RAW		#	Gross Motor Raw Score	See note 1.
VR_RAW		#	Visual Reception Raw Score	See note 1.
FM_RAW		#	Fine Motor Raw Score	See note 1.
RL_RAW		#	Receptive Language Raw Score	See note 1.
EL_RAW		#	Expressive Language Raw Score	See note 1.
GM_TSCR		#	Gross Motor T-Score	See note 2.
VR_TSCR		#	Visual Reception T-Score	See note 2.
FM_TSCR		#	Fine Motor T-Score	See note 2.
RL_TSCR		#	Receptive Language T-Score	See note 2.
EL_TSCR		#	Expressive Language T-Score	See note 2.
COM_SSCR		#	Early Learning Composite Standard Score	See note 3.
COM_PERC		#	Early Learning Composite Percentile Rank	See note 3.

Note 1: : Raw scores for the Mullen were calculated at clinical sites following administration (see Mullen, EM (1995). Mullen Scales of Early Learning: AGS Edition Item Administration Book & Manual. Minneapolis, MN: Pearson).

Note 2: Scale T-scores were calculated in Mullen software based on raw scores and child's age. T-scores are standardized to have a mean of 50 and standard deviation of 10 in a normative population (see manual).

Note 3: The Early Learning Composite Standard Score and Percentile Rank were calculated in Mullen software. This score is derived from the four cognitive scales (fine motor, visual reception, receptive language, and expressive language) and is standardized to have a mean of 100 and a standard deviation of 15 in a normative population (see manual).

Death (1 of 1)

SubjectID

Death Information

Information Regarding Death

Date of Death

DeathDay #

Time of Death

TimeDeath \$4

Cause of death

DV6032G

1 = Yes

2 = No

PertCauseDeath \$255

Withdrawal of support?

WithdrawSupport #

If died in PICU, was the subject DNR at the time of admission to the PICU?

PICUDNR #

Was an autopsy performed?

PICUAutopsy #

DV377G

1 = Autopsy not performed

2 = Autopsy performed

DV398G

1 = Yes

2 = No

3 = Unsure

Derived variables included in the Death dataset:

Variable	Format	Type	Label	Algorithm / Notes
DeathHosp	YESNO 1 = Yes 0 = No	#	Death in initial hospitalization	Based on data collected via queries outside of primary database.