

Public Use Dataset
Annotated eCRF

**Trichotomous Outcome Prediction in Critical Care
(The TOPICC Study) Phase II
CPCCRN Protocol Number 034**

Collaborative Pediatric Critical Care Research Network
Eunice Kennedy Shriver National Institute for Child
Health and Human Development (NICHD)

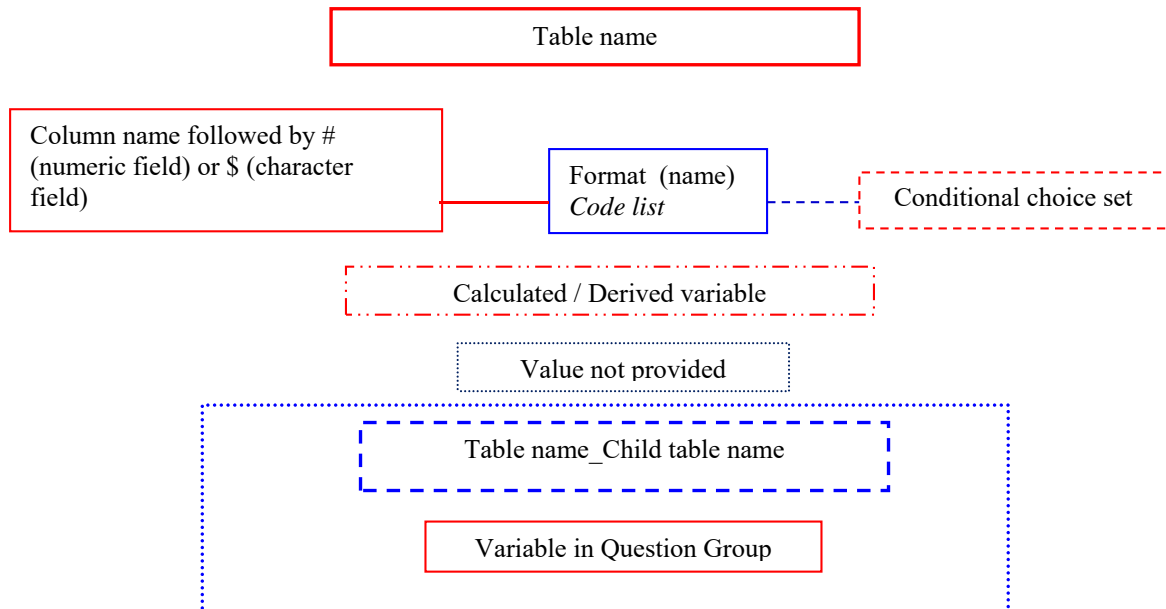
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Annotations key



Notes

StudySubjectID was replaced by PudID, sequential integers, that uniquely identifies a patient across datasets, it does not contain information about original site or medical record number. Occurrence and ItemGroupRepeatKey are also unique subject identifiers.

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.

'Date' variables are replaced with 'day' variables. Day variables are populated with the number of days since the reference date, ICU admission date. ICU admission date is coded as 0 (Day 0) and all other dates will be recoded as number of days after Day 0 (if any dates occur before the ICU admission day, these dates will have a negative value).

TOPICC Phase II Hospital Admission Information:

PudID #

Occurrence #

ItemGroupRepeatKey #

Demog (0/8) History (0/10) Baselin...(0/10) -- Select to Jump --

Title: Patient Demographics

Was this patient already enrolled in the TOPICC study during a previous hospitalization?

YesNo
1=Yes
0=No

PreviousEnroll, #

If yes, enter the EDC Subject ID for the first enrollment:

OriginalSubjectID, #

Date of birth: BirthDay, # (DD-MMM-YYYY)

Sex: ☐ Male ☐ Female *

Sex, #

Sex
1 = Male
2 = Female

Ethnicity, #

Ethnicity: ☐ Hispanic or Latino *
☐ Not Hispanic or Latino
☐ Unknown or Not Reported

Race: ☐ American Indian or Alaska Native *
(select all that apply)
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Unknown or Not Reported

Residential Zip Code: Value not provided

Please select the most appropriate primary payer type:

Payer, #

PayerTyp
1=Commercial Insurance
2=Medicaid
3=Medicare
4=Other Governmental Insurance
5=Self Pay
6=Worker's Compensation
90=Other
92=Unknown

Additional / derived variables included in the HOSPITALADMIT dataset:

Variable	Type	Label	Algorithm / Notes
RACE1	#	American Indian or Alaska Native	1 = Yes, 0 = No
RACE2	#	Asian	1 = Yes, 0 = No
RACE3	#	Black or African American	1 = Yes, 0 = No
RACE4	#	Native Hawaiian or Other Pacific Islander	1 = Yes, 0 = No
RACE5	#	White	1 = Yes, 0 = No
RACE92	#	Unknown or Not Reported	1 = Yes, 0 = No

HOSPITALADMIT (2 of 4)

TOPICC Phase II Hospital Admission Information:

Demog (0/10) History (0/10) Baselin...(0/16) -- Select to Jump --

Title: Historical Information

Hospital Admission Date and Time

Date: HOSPADMITDAY, # (DD-MMM-YYYY) Time: HospAdmitTime, \$ (HMM)

Was there a catastrophic event prior to hospital admission?

YesNo
1=Yes
0=No

BaselineCE, # HospitalAdmit_CE

Description of the catastrophic event	Other (specify)	Time interval since the catastrophic event **Prior to Hospital Admission**
BaselineCEDesc, #	BaselineCEDescOther, \$	BaselineCEInterval, #
ADD		

Is there known mental retardation or developmental delay prior to hospital admission?

DevelopDelay, # YesNo
1=Yes
0=No

Was this patient admitted to the hospital from the Emergency Department?

AdmitThroughED, # YesNo
1=Yes
0=No

Emergency Department Arrival Date and Time

Date: EDArrivalDay, # (DD-MMM-YYYY) Time: EDArrivalTime, \$ (HMM)

Event

1=Hypoxic Ischemic Encephalopathy
2=Cardiac Arrest
3=Respiratory Arrest
4= Traumatic Brain Injury
5= Spinal Cord Injury
6= Stroke
90=Other

TimeInt

1=< 12 hours
2=12 to < 24 hours
3=1 day to < 1 week
4=1 week to one month
5=Within last six months
6=Within last 12 months
7=> 12 months ago

FSS
 1=Normal
 2=Mild dysfunction
 3=Moderate dysfunction
 4=Severe dysfunction
 5=Very severe dysfunction

HOSPITALADMIT (3 of 4)

OPICC Phase II Hospital Admission Information:

HOSPADMITDAY, #

History (0/10)

Baseline... (0/10)

-- Select to Jump --

Baseline Functional Status

Instructions: This information is *ALL PRIOR TO* hospital admission (i.e. How did the child function prior to the event that brought him/her to the hospital).

Mental Status Classification:
☐ Normal
☐ Mild dysfunction
☐ Moderate dysfunction
☐ Severe dysfunction
☐ Very severe dysfunction

Baseline FSS Source: ☐ Medical record
 (check all that apply) ☐ Clinical caretaker

BaselineFSSMental, #

Sensory Classification:
☐ Normal
☐ Mild dysfunction
☐ Moderate dysfunction
☐ Severe dysfunction
☐ Very severe dysfunction

BaselineFSSSensory, #

Communication Classification:
☐ Normal
☐ Mild dysfunction
☐ Moderate dysfunction
☐ Severe dysfunction
☐ Very severe dysfunction

BaselineFSSCommun, #

Motor Function Classification:
☐ Normal
☐ Mild dysfunction
☐ Moderate dysfunction
☐ Severe dysfunction
☐ Very severe dysfunction

BaselineFSSMotor, #

Feeding Classification:
☐ Normal
☐ Mild dysfunction
☐ Moderate dysfunction
☐ Severe dysfunction
☐ Very severe dysfunction

BaselineFSSFeeding, #

Respiratory Classification:
☐ Normal
☐ Mild dysfunction
☐ Moderate dysfunction
☐ Severe dysfunction
☐ Very severe dysfunction

BaselineFSSResp, #

Additional / derived variables included in the HOSPITALADMIT dataset:

Variable	Type	Label	Algorithm / Notes
BaselineFSSSource1	#	Medical Caretaker	1 = Yes, 0 = No
BaselineFSSSource2	#	Clinical Caretaker	1 = Yes, 0 = No

TOPICC Phase II Hospital Admission Information:

PCPC
 1= 1 – Normal
 2= 2 - Mild disability
 3= 3 - Moderate disability
 4= 4 - Severe disability
 5= 5 - Coma/vegetative

BaselinePCPC, #

Pediatric Cerebral Performance Category (PCPC)

PCPC: ☐ 1 - Normal
☐ 2 - Mild disability
☐ 3 - Moderate disability
☐ 4 - Severe disability
☐ 5 - Coma/vegetative

Baseline PCPC / POPC ☐ Medical record
 Source: ☐ Clinical caretaker
 (check all that apply)

Pediatric Overall Performance Category (POPC)

POPC: ☐ 1 - Good
☐ 2 - Mild disability
☐ 3 - Moderate disability
☐ 4 - Severe disability
☐ 5 - Coma/vegetative

BaselinePOPC, INT

POPC
 1= 1 – Good
 2= 2 - Mild disability
 3= 3 - Moderate disability
 4= 4 - Severe disability
 5= 5 - Coma/vegetative

Additional / derived variables included in the HOSPITALADMIT dataset:

Variable	Type	Label	Algorithm / Notes
BaselinePCPCSource1	#	Medical Caretaker	1 = Yes, 0 = No
BaselinePCPCSource2	#	Clinical Caretaker	1 = Yes, 0 = No

PICUADMIT (1 of 3)

TOPICC Phase II PICU Admission Information:

PudID #

Occurrence #

ItemGroupRepeatKey #

PICUAdm... (0/12) PICUDx (0/7) CardioDx (0/6) -- Select to Jump --

Title: PICU Admission Information

PICU Admission Date and Time

Date: (DD-MMM-YYYY) Time:

Admission Status:

Which PICU did the patient get admitted to?

PICUAdm
1 = Medical/Surgical
2 = Cardiac
90 = Other

Has the patient been admitted for postoperative care?

☒ If yes, provide post operative type

Postoperative admission type: If "Cardiac" is selected, complete the Cardiac Surgery form. Other (specify):

Name of Surgery?

Who is the clinical service with primary responsibility?

What is the admission source?

What was the nurse to patient ratio for this patient's PICU admission shift?

What was the nurse to patient ratio for this patient's second (next) PICU shift?

NPR
1=> 1 nurse : 1 patient
2=1 nurse : 1 patient
3=1 nurse : 2 patients
4=1 nurse : > 2 patients

AdmitLoc
1=Direct admission from outside of the study hospital
2=Study hospital emergency department
3=Study hospital general care floor
4=Study hospital intermediate care unit
5=Study hospital other ICU
6=Study hospital monitoring unit
7=Study hospital operating room
8=Study hospital other location

SurgType
1=Cardiac
2=Interventional cardiac catheterization
3=Neurosurgery
4=Orthopedic
5=Transplant
6=Trauma
7=General surgery
8=ENT
90=Other

SCD
1=Adult medical/surgical
3=Anesthesiology/pain
5=Cardiovascular surgery
7=Critical/intensive care (cardiac)
9=Endocrinology
11=Gastroenterology
13=General surgery
15=Hematology/oncology
17=Metabolic
19=Neurology
21=Ophthalmology
23=Orthopedic surgery
25=Psychiatry
27=Renal/nephrology
29=Trauma surgery
90=Other

2=Allergy/immunology
4=Cardiology
6=Critical/intensive care (general)
8=Critical/intensive care (neurology)
10=Ear/Nose/Throat surgery
12=General pediatrics
14=Genetics
16=Infectious diseases
18=Miscellaneous surgery
20=Neurosurgery
22=Oral surgery/dentistry
24=Plastic surgery
26=Pulmonary
28=Rheumatology
30=Urologic surgery

PICUADMIT (2 of 3)

TOPICC Phase II PICU Admission Information:

PrimDiag

- | | |
|--|--|
| 1=Airway/tracheal abnormality, obstruction, surgery | 2=Asthma |
| 3=Cancer | 4=Cardiac arrest |
| 5=Cardiovascular disease – acquired | 6=Cardiovascular disease – arrhythmia |
| 7=Cardiovascular disease – congenital | 8=Central nervous system infection |
| 9=Congenital anomaly or chromosomal defect | 10=Diabetic ketoacidosis (DKA) |
| 11=Drowning / asphyxia / hanging | 12=Gastrointestinal disorder |
| 13=Hematologic disorder | 14=Ingestion (drug or toxin) |
| 15=Musculoskeletal condition | 16=Neurological miscellaneous |
| 17=Neurological - cords, bones | 18=Neurological – vascular malformations |
| 19=Neurological CSF related (hydrocephalus / Chiari / fenestrations / arachnoid cysts) | 21=Renal failure |
| 20=Pertussis | 23=Scoliosis / spine surgery |
| 22=Respiratory distress / failure | 25=Sepsis / SIRS / Septic shock |
| 24=Seizures | 27=Transplant |
| 26=Stroke / Cerebral Ischemia / Cerebral infarction | 90=Other miscellaneous |
| 28=Trauma | |

PICUAdm... (0/12) **PICUDx** (0/8) **CardioDx** (0/5)

Title: Diagnoses

Instructions: Primary, secondary, and chronic diagnoses information is based on admission notes.

Primary Acute Diagnosis: **PICUAdmitPrimaryDx, #** Other (specify): **PICUAdmitPrimaryDxOther, \$**

Are there any secondary acute diagnoses upon PICU admission?

PICUAdmitSecondDx, # If yes, provide diagnoses below.

Secondary Acute Diagnoses	Other (specify)
PICUAdmitSecondDxCat, #	PICUAdmitSecondDxOther, \$
ADD	

Does the patient have any chronic diagnoses?

PICUAdmitChronicDx, # If yes, provide diagnoses below.

Chronic Diagnoses	Other (specify)
PICUAdmitChronicDxCat, #	PICUAdmitChronicDxOther, \$
ADD	

YesNo
1=Yes
0=No

Diag

- | | |
|---------------------------------------|-------------------------------------|
| 1=Asthma | 2=Cancer |
| 3=Cardiac arrest w/in 24hrs | 4=Chromosomal abnormality |
| 5=Diabetes | 6=Drug overdose |
| 7=Gastroesophageal reflux | 8=Cardiovascular disease – acquired |
| 9=Cardiovascular disease – congenital | 10=HIV infection |
| 11=Hypoxic-ischemic encephalopathy | 12=Medical device malfunction |
| 13=Meningitis | 14=Pneumonia/bronchiolitis |
| 15=Seizures | 16=Sepsis |
| 17=Shock | 18=Suicide attempt |
| 19=Transplant | 20=Trauma |
| 90=Other | |

ChronDz

- | |
|--|
| 1=Asthma |
| 2=Cancer |
| 3=Cardiovascular disease – acquired |
| 4=Cardiovascular disease – arrhythmia |
| 5=Cardiovascular disease – congenital |
| 6=Chronic renal failure |
| 7=Chronic lung disease (BPD, CF) |
| 8=Congenital anomaly or chromosomal defect |
| 9=Diabetes |
| 10=Musculoskeletal |
| 11=Neurologic - static encephalopathy |
| 12=Neurologic - Other chronic condition |
| 13=Neurologic - chronic seizures |
| 14=Transplant |
| 90=Other |

TOPICCII Annotated eCRF, v1.0_07Jul2016

TOPICC Phase II PICU Admission Information:

PICUAdm... (0/12) PICUDx (0/8) CardioDx (0/5) -- Select to Jump --

Title: Cardiovascular Disease

Instructions: Assess the following diagnoses from the cardiology and/or cardiovascular surgery medical record entries.

Does the patient have congenital heart disease?

CHD, # If yes, provide diagnoses below.

Congenital Heart Disease
(all that apply at time of PICU admission)

PICUAdmit_CHD

CHDCat, #

Does the patient have acquired heart disease?

AcquiredHeart, # If yes, provide diagnoses below.

Acquired Heart Disease,
NOT progression of congenital heart disease
(all that apply at time of PICU admission)

PICUAdmit_AHD

AcquiredHeartCat, #

Other (specify)

AcquiredHeartCatOther, \$

YesNo
1=Yes
0=No

AHD
1=Arrhythmia
2=Cardiac arrest
3=Cardiomyopathy
4=Congestive heart failure
5=Kawasaki's disease
6=Myocarditis
7=Overdose with cardiac affects
8=Rheumatic fever
9=Supraventricular tachycardia
10=Transplant rejection
11=Tumor
12=Vasculitis
90=Other

CHD
1=Anomalous coronary artery
3=total Anomalous pulm vein return (TAPVR)
5=Aortic stenosis (atresia)
7=Atrioventricular canal
9=Atrial septal defect (secundum)
11=Coarctation of the aorta
13=Cor triatriatum
15=Ebstein's anomaly
17=Hypoplastic left heart syndrome
19=Mitral insufficiency
21=Patent ductus arteriosus
23=Pulmonary hypertension
25=Single ventricle
27=Tetralogy of Fallot
29=Tricuspid stenosis / atresia
31=Ventricular septal defect
33=Other non-cyanotic heart disease

2=partial Anomalous pulm vein return (PAPVR)
4=Aortic insufficiency
6=Arrhythmia (e.g. WPW syndrome)
8=Atrial septal defect (primum)
10=Cardiac arrest
12=Congestive heart failure
14=Double outlet right ventricle
16=Hypoplastic aortic arch
18=Hypoplastic right heart syndrome
20=Mitral stenosis (atresia)
22=Pulmonary atresia
24=Pulmonary stenosis
26=s/p central/BT shunt
28=Transposition of the great vessels
30=Truncus arteriosus
32=Other cyanotic heart disease

PHYSIOSTATUS (1 of 4)

TOPICC Phase II Physiological Status Logs:

PudID #

Occurrence #

ItemGroupRepeatKey #

◀ BloodGas (0/10) Electro... (0/18) CBC_Coag (0/14) ▶ -- Select to Jump -- ▼

Title: Blood Gas Labs

Instructions: Please record the blood gas values specified below obtained during the time window of 2 hours prior to PICU admission through 4 hours post-PICU admission. If only one value is available for this time window, the lowest and highest values are the same. If a specific blood gas lab was not obtained during the time window, select "not done." PaO2 MUST be from an arterial specimen.

pH

Lowest pH: LowpH, # (##.##)

Highest pH: HighpH, # (##.##) ☐ Not done pHND, #

PCO2

Highest PCO2: HighPCO2, # (mmHg) ☐ Not done PCO2ND, #

PaO2

Lowest PaO2: LowPaO2, # (mmHg) ☐ Not done PaO2ND, #

Ionized Calcium

Lowest Ionized Calcium: LowIonCalcium, # (g/dL) ☐ Not done

uncorrected for pH

Highest Ionized Calcium: HighIonCalcium, # (dL) ☐ Not done IonCalciumND, #

uncorrected for pH

NotDone
95=Not done

PHYSIOSTATUS (2 of 4)

TOPICC Phase II Physiological Status Logs:

BloodGas (0/10)
Electro... (0/18)
CBC_Coag (0/14)
-- Select to Jump --

Title: Electrolyte Labs

Instructions: Please record the electrolyte values specified below obtained during the time window of 2 hours prior to PICU admission through 4 hours post-PICU admission. If only one value is available for this time window, the lowest and highest values are the same. If a specific electrolyte lab was not obtained during the time window, select "not done."

Sodium			
Lowest Sodium:	<div style="border: 1px solid red; padding: 2px;">LowSodium, #</div>		
Highest Sodium:	<div style="border: 1px solid red; padding: 2px;">HighSodium, #</div>	<input type="checkbox"/> Not done	<div style="border: 1px solid red; padding: 2px;">SodiumND, #</div>
Potassium			
Highest Potassium:	<div style="border: 1px solid red; padding: 2px;">HighPotassium, #</div>	<input type="checkbox"/> Not done	<div style="border: 1px solid red; padding: 2px;">PotassiumND, #</div>
Blood Urea Nitrogen			
Highest BUN:	<div style="border: 1px solid red; padding: 2px;">HighBUN, #</div> mg/dL	<input type="checkbox"/> Not done	<div style="border: 1px solid red; padding: 2px;">HighBUNND, #</div>
Creatinine			
Highest Creatinine:	<div style="border: 1px solid red; padding: 2px;">HighCreatinine, #</div>	<input type="checkbox"/> Not done	<div style="border: 1px solid red; padding: 2px;">CreatinineND, #</div>
Glucose			
Lowest Glucose:	<div style="border: 1px solid red; padding: 2px;">LowGlucose, #</div>		
Highest Glucose:	<div style="border: 1px solid red; padding: 2px;">HighGlucose, #</div>	<input type="checkbox"/> Not done	<div style="border: 1px solid red; padding: 2px;">GlucoseND, #</div>
Total Serum CO2			
Lowest Total Serum CO2:	<div style="border: 1px solid red; padding: 2px;">LowCO2, #</div> mmol/L		
Highest Total Serum CO2:	<div style="border: 1px solid red; padding: 2px;">HighCO2, #</div> mmol/L	<input type="checkbox"/> Not done	<div style="border: 1px solid red; padding: 2px;">CO2ND, #</div>
Total Calcium			
Lowest Total Calcium:	<div style="border: 1px solid red; padding: 2px;">LowTotalCalcium, #</div>		
Highest Total Calcium:	<div style="border: 1px solid red; padding: 2px;">HighTotalCalcium, #</div>	<input type="checkbox"/> Not done	<div style="border: 1px solid red; padding: 2px;">TotalCalciumND, #</div>

NotDone
95=Not done

PHYSIOSTATUS (3 of 4)

TOPICC Phase II Physiological Status Logs:

Electro... (0/18)
CBC_Coag (0/14)
Vitals (0/8)
▶ -- Select to Jump -- ▼

Title: Complete Blood Count and Coagulation Labs

Instructions: Please record the CBC and coagulation values specified below obtained during the time window of 2 hours prior to PICU admission through 4 hours post-PICU admission. If only one value is available for this time window, the lowest and highest values are the same. If a specific CBC or Coag lab was not obtained during the time window, select "not done."

White Blood Cells

Lowest WBC: LowWBC, # ^{10³/uL}

Highest WBC: HighWBC, # ^{10³/uL} ☐ Not done WBCND, #

Hemoglobin

Lowest Hgb: LowHemoglobin, #

Highest Hgb: HighHemoglobin, # ☐ Not done HemoglobinND, #

Platelets

Lowest Platelets: LowPlatelets, # ^{10³/uL} ☐ Not done PlateletsND, #

Prothombin Time

Highest PT: HighPT, # (seconds) ☐ Not done PTND, #

Partial Thromboplastin Time

Highest PTT: HighPTT, # (seconds) ☐ Not done PTTND, #

International Normalized Ratio

Highest INR: HighINR, # (%) ☐ Not done INRND, #

CBC_Coag (0/14)
Vitals (0/8)
NeuroAs... (0/7)
▶ -- Select to Jump -- ▼

Title: Vital Measurements

Instructions: The highest and lowest vital measurement values will be obtained from the vitals taken during 0 hours to 4 hours post-PICU admission ONLY. Please do not include vitals taken during the operating room period in surgical patients.

Temperature

Highest Temperature: HighTemp, # Lowest Temperature: LowTemp, #

Respiratory Rate

Highest Respiratory Rate: HighRespRate, # Lowest Respiratory Rate: LowRespRate, #

Heart Rate

Highest Heart Rate: HighHeartRate, INT Lowest Heart Rate: LowHeartRate, #

Systolic Blood Pressure

Highest Systolic BP: HighSBP, # Lowest Systolic BP: LowSBP, #

PHYSIOSTATUS (4 of 4)

TOPICC Phase II Physiological Status Logs:

CBC_Coag (0/14)
Vitals (0/8)
NeuroAs...(0/7)
-- Select to Jump --

Title: Neurological Assessments

Instructions: The "worst" scores are to be obtained during 0 to 4 hours post-PICU admission.

Neurological Injury

Is there reasonable suspicion of possible neurological injury for this patient?

☐

CNSInjury, #

YesNo
 1=Yes
 0=No

GCS Scores

Please note: The GCS motor and total scores must be obtained from the same assessment. Both scores come from the worst GCS motor score assessment.

Worst Motor Score:

GCSWorstMotor, #

Worst Total Score:

GCSWorstTotal, #

MotorGCS
 1=1
 2=2
 3=3
 4=4
 5=5
 6=6
 93=Unable to assess

Was the patient intubated at the time of GCS assessment?

YesNo
 1=Yes
 0=No

GCSIntub, #

YesNo
 1=Yes
 0=No

Level of consciousness

Worst LOC Status:

LOCWorst, #

LOCWorst
 1=No Coma
 2=Coma (unresponsive)
 93=Unable to assess

Pupillary reflexes

Worst pupillary reflexes:

PupilWorst, #

Pupil
 1=Both reactive
 2=One non-reactive (>3mm)
 3=Both non-reactive (>3mm)
 4=Both pupils<3mm, cannot be scored

Were the worst pupillary reflexes due to the patient being hypothermic below 34 °C?

PupilHypo, #

YesNo
 1=Yes
 0=No

CAREPROCESSES (1 of 1)

TOPICC Phase II PICU Care Processes:

PudID #

Occurrence #

ItemGroupRepeatKey #

PICUCare (0/12) -- Select to Jump --

Title: PICU Care Processes

During the PICU stay, did any of the following occur at any time?

Mechanical ventilation:	MechVent, #	<div>YesNo</div> <div>1=Yes</div> <div>0=No</div>
High Frequency Ventilation (oscillator or jet):	HFOV, #	
Nitric oxide:	NOX, #	
Intracranial pressure monitoring:	ICP, #	
Therapeutic hypothermia:	TherapeuticHypo, #	
Vasoactive infusions:	VasoInf, #	
Antibiotic administration:	AbxAdmin, #	
Steroid administration:	SteroidAdmin, #	
Neuromuscular blockade:	NeuroBlock, #	
Extracorporeal support (ECMO or VAD):	ECMO, #	
Renal replacement therapy (hemofiltration or dialysis):	RenalReplace, #	
Parenteral nutrition:	ParentNutrition, #	

TOPICC Phase II PICU Discharge Information:

PudID #

Occurrence #

ItemGroupRepeatKey #

Title: PICU Discharge Information

Date and Time of PICU Discharge

Date: (DD-MMM-YYYY) Time: (HHMM)

During the PICU stay, did any of the following occur at any time:

Surgical procedure after PICU admission? (select one) If yes, complete the Surgery During PICU Course form, and, if applicable, the Cardiac Surgery form

Cardiopulmonary resuscitation? (select one) If yes, complete CPR form

A discussion concerning limitations or withdrawal of care? (select one) If yes, complete the limitations/withdrawal of care form.

Was the patient alive at the time of PICU discharge?

If no, complete the Hospital Death form. You have completed data entry for this form.

Discharging Clinical Service:

Transfer Location: (Note: PICU + CICU = same admission)

YesNo
1=Yes
0=No

TRFLOC
1=Step-down unit
2=Hospital general care unit
3=Another ICU in the same hospital
4=In-patient rehabilitation
5=Chronic care facility
6=Another hospital
7=Home

SCD
1=Adult medical/surgical
3=Anesthesiology/pain
5=Cardiovascular surgery
7=Critical/intensive care (cardiac)
9=Endocrinology
11=Gastroenterology
13=General surgery
15=Hematology/oncology
17=Metabolic
19=Neurology
21=Ophthalmology
23=Orthopedic surgery
25=Psychiatry
27=Renal/nephrology
29=Trauma surgery
90=Other

2=Allergy/immunology
4=Cardiology
6=Critical/intensive care (general)
8=Critical/intensive care (neurology)
10=Ear/Nose/Throat surgery
12=General pediatrics
14=Genetics
16=Infectious diseases
18=Miscellaneous surgery
20=Neurosurgery
22=Oral surgery/dentistry
24=Plastic surgery
26=Pulmonary
28=Rheumatology
30=Urologic surgery

TOPICC Phase II PICU Discharge Information:

PICUDis... (0/8) PICUDx (0/8) Dischar... (0/10) -- Select to Jump --

Title: PICU Discharge Diagnoses

Instructions: Please record all primary, secondary, and chronic diagnoses based on discharge notes

Primary Diagnosis: Other (specify):

Were there any secondary diagnoses upon PICU discharge?

If yes, provide diagnoses below.

Secondary Diagnoses:	Other (specify):
<input type="text" value="PICUDisSecondDxCat, #"/>	<input type="text" value="PICUDisSecondDxOther, \$"/>
<input type="button" value="ADD"/>	<input type="button" value="X"/>
<input type="text" value="PICUDischarge_DisSecondDx"/>	

YesNo
1=Yes
0=No

Has the patient been diagnosed with any new chronic diagnoses since being admitted to the PICU?

If yes, provide diagnoses below.

Chronic Diagnoses:	Other (specify):
<input type="text" value="PICUDisChronicDxCat, #"/>	<input type="text" value="PICUDisChronicDxOther, \$"/>
<input type="button" value="ADD"/>	<input type="button" value="X"/>
<input type="text" value="PICUDischarge_DisChronicDx"/>	

Diag

1=Asthma	2=Cancer
3=Cardiac arrest w/in 24hrs	4=Chromosomal abnormality
5=Diabetes	6=Drug overdose
7=Gastroesophageal reflux	8=Cardiovascular disease - acquired,
9=Cardiovascular disease – congenital	10=HIV infection
11=Hypoxic-ischemic encephalopathy	12=Medical device malfunction,
13=Meningitis	14=Pneumonia/bronchiolitis
15=Seizures	16=Sepsis
17=Shock	18=Suicide attempt
19=Transplant	20=Trauma
90=Other	

PrimDiag

1=Airway/tracheal abnormality, obstruction, surgery	2=Asthma
3=Cancer	4=Cardiac arrest
5=Cardiovascular disease – acquired	6=Cardiovascular disease – arrhythmia
7=Cardiovascular disease – congenital	8=Central nervous system infection
9=Congenital anomaly or chromosomal defect	10=Diabetic ketoacidosis (DKA)
11=Drowning / asphyxia / hanging	12=Gastrointestinal disorder
13=Hematologic disorder	14=Ingestion (drug or toxin)
15=Musculoskeletal condition	16=Neurological miscellaneous
17=Neurological - cords, bones	18=Neurological - vascular malformations
19=Neurological CSF related (hydrocephalus/ Chiari/fenestrations/arachnoid cysts)	20=Pertussis
21=Renal failure	22=Respiratory distress/failure
23=Scoliosis/spine surgery	24=Seizures
25=Sepsis/SIRS/Septic shock	26=Stroke/Cerebral Ischemia/Cerebral infarction
27=Transplant	28=Trauma
90=Other miscellaneous	

ChronDz

1=Asthma	2=Cancer
3=Cardiovascular disease – acquired	4=Cardiovascular disease – arrhythmia
5=Cardiovascular disease – congenital	6=Chronic renal failure
7=Chronic lung disease (BPD, CF)	8=Congenital anomaly or chromosomal defect
9=Diabetes	10=Musculoskeletal
11=Neurologic - static encephalopathy	12=Neurologic - Other chronic condition
13=Neurologic - chronic seizures	14=Transplant
90=Other	

TOPICC Phase II PICU Discharge Information:

PICUDx (0/8) Dischar... (0/10) MedAndO... (0/9) -- Select to Jump --

Title: PICU Discharge Functional Status

Mental Status Classification: ☐ Normal ☐ Mild dysfunction ☐ Moderate dysfunction ☐ Severe dysfunction ☐ Very severe dysfunction

PICUDisFSSMental, #

PICU Discharge FSS Source: (check all that apply) ☐ Medical record ☐ Clinical caretaker ☐ Direct observation

Sensory Classification: ☐ Normal ☐ Mild dysfunction ☐ Moderate dysfunction ☐ Severe dysfunction ☐ Very severe dysfunction

PICUDisFSSSensory, #

Communication Classification: ☐ Normal ☐ Mild dysfunction ☐ Moderate dysfunction ☐ Severe dysfunction ☐ Very severe dysfunction

PICUDisFSSCommun, #

Motor Function Classification: ☐ Normal ☐ Mild dysfunction ☐ Moderate dysfunction ☐ Severe dysfunction ☐ Very severe dysfunction

PICUDisFSSMotor, #

Feeding Classification: ☐ Normal ☐ Mild dysfunction ☐ Moderate dysfunction ☐ Severe dysfunction ☐ Very severe dysfunction

PICUDisFSSFeeding, #

Respiratory Classification: ☐ Normal ☐ Mild dysfunction ☐ Moderate dysfunction ☐ Severe dysfunction ☐ Very severe dysfunction

PICUDisFSSResp, #

FSS
1=Normal
2=Mild dysfunction
3=Moderate dysfunction
4=Severe dysfunction
5=Very severe dysfunction

Additional / derived variables included in the PICUDISCHARGE dataset:

Variable	Type	Label	Algorithm / Notes
PICUDisFSSSource1	#	Medical record	1 = Yes, 0 = No
PICUDisFSSSource2	#	Clinical caretaker	1 = Yes, 0 = No
PICUDisFSSSource3	#	Direct observation	1 = Yes, 0 = No

TOPICC Phase II PICU Discharge Information:

Pediatric Cerebral Performance Category (PCPC)

PCPC: ☐ 1 - Normal
☐ 2 - Mild disability
☐ 3 - Moderate disability
☐ 4 - Severe disability
☐ 5 - Coma/vegetative

PICUDisPCPC, #

PICU Discharge PCPC / POPC Source: (check all that apply)
☐ Medical record
☐ Clinical caretaker
☐ Direct observation

Pediatric Overall Performance Category (POPC)

POPC: ☐ 1 - Good
☐ 2 - Mild disability
☐ 3 - Moderate disability
☐ 4 - Severe disability
☐ 5 - Coma/vegetative

PICUDisPOPC, #

PCPC
 1=1 - Normal
 2=2 - Mild disability
 3=3 - Moderate disability
 4=4 - Severe disability
 5=5 - Coma/vegetative

POPC
 1=1 - Good
 2=2 - Mild disability
 3=3 - Moderate disability
 4=4 - Severe disability
 5=5 - Coma/vegetative

Additional / derived variables included in the PICUDISCHARGE dataset:

Variable	Type	Label	Algorithm / Notes
PICUDisPCPCSource1	#	Medical record	1 = Yes, 0 = No
PICUDisPCPCSource2	#	Clinical caretaker	1 = Yes, 0 = No
PICUDisPCPCSource3	#	Direct observation	1 = Yes, 0 = No

TOPICC Phase II PICU Discharge Information:

[PICUDx \(0/8\)](#)
[Dischar...\(0/10\)](#)
[MedAndO...\(0/9\)](#)
-- Select to Jump --

Title: PICU Discharge Medication and Other Relevant Factors Status

Relevant Medications

Was neuromuscular blockade administered in the 24 hours prior to the PICU discharge FSS assessment?

PICUDisNeuroBlock, #

Indicate if any of the following were given in the 4 hours prior to the PICU discharge FSS assessment:

Sedatives? PICUDisSedative, #

Narcotics? PICUDisNarcotic, #

Other pain medications? PICUDisOtherPain, #

Sleeping aids? PICUDisSleepingAid, #

Other drugs affecting functional status? PICUDisOtherDrugs, #

Other Relevant Factors

At the time of the PICU discharge FSS assessment, were any of the following present preventing extremity function:

Arm and/or foot boards? PICUDisArmFootBoards, #

Soft or hard restraints? PICUDisRestraints, #

Bandages or casts? PICUDisBandageCast, #

YesNo
1=Yes
0=No

HOSPITALDISCHARGE (1 of 4)

TOPICC Phase II Hospital Discharge Information:

PudID #

Occurrence #

ItemGroupRepeatKey #

Hospita...(0/8)
Dischar...(0/10)
MedAndO...(0/9)
▶ -- Select to Jump -- ▼

Title: Hospital Discharge

Record date and time of hospital discharge

Date: HospDisDay, # (DD-MMM-YYYY) Time: HospDisTime, \$ (HHMM)

After the initial PICU discharge was the patient re-admitted to the PICU at anytime during the hospital stay?

HospDisReadmit, #

Did any catastrophic events occur during the hospitalization?

HospCE, # If yes, complete the catastrophic events form.

Was the patient alive at the time of hospital discharge?

HospDisAlive, # If no, complete a death form. You have completed data entry for this form.

Location to where patient was discharged:

HospDisLoc, # Other (specify): HospDisLocOther, \$

Was the patient discharged to hospice care?

HospDisHospice, #

DisLoc

1=Home or foster care

2=Another acute care hospital

3=Acute inpatient rehabilitation unit

4=Chronic care or skilled nursing facility

90=Other

YesNo

1=Yes

0=No

TOPICC Phase II Hospital Discharge Information:

Hospita...(0/8) Dischar...(0/10) MedAnd0...(0/9) -- Select to Jump --

Title: Discharge Functional Status

Mental Status Classification:
 ☐ Normal
 ☐ Mild dysfunction
 ☐ Moderate dysfunction
 ☐ Severe dysfunction
 ☐ Very severe dysfunction

HospDisFSSMental, #

Hospital Discharge FSS Source: (check all that apply)
 ☐ Medical record
 ☐ Clinical caretaker
 ☐ Direct observation

HospDisFSSSource1, #

HospDisFSSSource2, #

HospDisFSSSource3, #

Sensory Classification:
 ☐ Normal
 ☐ Mild dysfunction
 ☐ Moderate dysfunction
 ☐ Severe dysfunction
 ☐ Very severe dysfunction

HospDisFSSSensory, #

Communication Classification:
 ☐ Normal
 ☐ Mild dysfunction
 ☐ Moderate dysfunction
 ☐ Severe dysfunction
 ☐ Very severe dysfunction

HospDisFSSCommun, #

Motor Function Classification:
 ☐ Normal
 ☐ Mild dysfunction
 ☐ Moderate dysfunction
 ☐ Severe dysfunction
 ☐ Very severe dysfunction

HospDisFSSMotor, #

Feeding Classification:
 ☐ Normal
 ☐ Mild dysfunction
 ☐ Moderate dysfunction
 ☐ Severe dysfunction
 ☐ Very severe dysfunction

HospDisFSSFeeding, #

Respiratory Classification:
 ☐ Normal
 ☐ Mild dysfunction
 ☐ Moderate dysfunction
 ☐ Severe dysfunction
 ☐ Very severe dysfunction

HospDisFSSResp, #

FSS
 1=Normal
 2=Mild dysfunction
 3=Moderate dysfunction
 4=Severe dysfunction
 5=Very severe dysfunction

Additional / derived variables included in the HOSPITALDISCHARGE dataset:

Variable	Type	Label	Algorithm / Notes
HospDisFSSSource1	#	Medical record	1 = Yes, 0 = No
HospDisFSSSource2	#	Clinical caretaker	1 = Yes, 0 = No
HospDisFSSSource3	#	Direct observation	1 = Yes, 0 = No

TOPICC Phase II Hospital Discharge Information:

PCPC
 1=1 – Normal
 2=2 - Mild disability
 3=3 - Moderate disability
 4=4 - Severe disability
 5=5 - Coma/vegetative

Pediatric Cerebral Performance Category (PCPC)
 PCPC: ☐ 1 - Normal
 ☐ 2 - Mild disability
 ☐ 3 - Moderate disability
 ☐ 4 - Severe disability
 ☐ 5 - Coma/vegetative
 Hospital Discharge ☐ Medical record
 PCPC / POPC source: ☐ Clinical caretaker
 ☐ Direct observation
 (check all that apply)

Pediatric Overall Performance Category (POPC)
 POPC: ☐ 1 - Good
 ☐ 2 - Mild disability
 ☐ 3 - Moderate disability
 ☐ 4 - Severe disability
 ☐ 5 - Coma/vegetative

POPC
 1=1 – Good
 2=2 - Mild disability
 3=3 - Moderate disability
 4=4 - Severe disability
 5=5 - Coma/vegetative

Additional / derived variables included in the HOSPITALDISCHARGE dataset:

Variable	Type	Label	Algorithm / Notes
HospDisPCPCInfo1	#	Medical record	1 = Yes, 0 = No
HospDisPCPCInfo2	#	Clinical caretaker	1 = Yes, 0 = No
HospDisPCPCInfo3	#	Direct observation	1 = Yes, 0 = No

TOPICC Phase II Hospital Discharge Information:

Hospita...(0/8) Dischar...(0/10) **MedAndO...(0/9)** -- Select to Jump --

Title: Discharge Medications and Other Relevant Factors Status

Relevant Medications

Was neuromuscular blockade administered in the 24 hours prior to the hospital discharge FSS assessment?

HospDisNeuroBlock, #

Indicate if any of the following were given in the 4 hours prior to the hospital discharge FSS assessment:

Sedatives? HospDisSedative, #

Narcotics? HospDisNarcotic, #

Other pain medications? HospDisOtherPain, #

Sleeping aids? HospDisSleepingAid, #

Other drugs affecting functional status? HospDisOtherDrugs, #

Other Relevant Factors

At the time of the hospital discharge FSS assessment, were any of the following present preventing extremity function:

Arm and/or foot boards? HospDisArmFootBoards, #

Soft or hard restraints? HospDisRestraints, #

Bandages or casts? HospDisBandageCast, #

YesNo
 1=Yes
 0=No

TOPICC Phase II Limitations/Withdrawals of Care:

Family (0/25) -- Select to Jump --

Title: Family Discussions Regarding Limitations of Care

Instructions: If there were discussions or decisions involving limitation or withdrawal of care (the processes by which specific interventions are not initiated or are discontinued with the expectation that death will occur as a result) during the patient's initial PICU stay, regardless of whether the patient ultimately died, data will be collected. Note that discussions of these end of life topics may have been held without ultimately deciding to limit or withdraw care. In these circumstances, data are still expected.

Record the date and time FIRST discussion took place concerning limitation or withdrawal of care

Date: WOCFamilyDiscussDay, # (MM-YYYY) Time: WOCFamilyDiscussTime, \$

Record the date and time when limitation or withdrawal of care was first discussed in the medical record

Date: WOCMedicalRecordDay, # (MM-YYYY) Time: WOCMedicalRecordTime, \$

Did any palliative care consultations occur?

PalliativeCare, # If yes, please record the date and time of FIRST palliative care consultation.

Date: PalliativeCareDay, # (DD-MMM-YYYY) Time: PalliativeCareTime, \$

Did any pain service consultations occur?

PainService, INT If yes, please record the date and time of FIRST pain service consultation.

Date: PainServiceDay, # (DD-MMM-YYYY) Time: PainServiceTime, \$

Did any ethics consultations occur?

Ethics, # If yes, please record the date and time of FIRST ethics consultation.

Date: EthicsDay, # (DD-MMM-YYYY) Time: EthicsTime, \$ (HHMM)

Limitations of future care

Were any of the following limited:

Mechanical ventilation? FutureMechVent, # Vasoactive medications? FutureVasoMeds, #

Cardiac compressions? (select one) FutureCardiacComp, # ECMO or VAD? FutureECMO, #

Dialysis or other renal replacement therapy? FutureDialysis, #

Withdrawals of already instituted care

Were any of the following discontinued or weaned in anticipation of death:
*Please Note: This does NOT include withdrawals after diagnosis of brain death.

Mechanical ventilation? WithdrawMechVent, # Vasoactive medications? WithdrawVasoMeds, #

Fluids or feeding? WithdrawFeeding, # ECMO or VAD? WithdrawECMO, #

Renal replacement therapy? WithdrawRRT, #

Other? WithdrawOther, # (specify): WithdrawOtherSpecify, \$

YesNo
1=Yes
0=No

YesNo
1=Yes
0=No

TOPICC Phase II Cardiopulmonary Resuscitation:

PudID #

Occurrence #

ItemGroupRepeatKey #

CPR (0/13) -- Select to Jump --

Title: Cardiopulmonary Resuscitation

Instructions: Complete the information for patients who receive closed or open chest cardiopulmonary resuscitation (compressions or defibrillation) in the PICU for each occurrence that is separated by at least 20 minutes of spontaneous circulation. Note: For patients with multiple arrests (who do not have a return of spontaneous circulation for at least 20 minutes between episodes) the event is considered one arrest. One CPR form should be completed. However, if there is a ROC greater than or equal to 20 minutes between episodes, complete a new CPR form per subsequent arrest.

Date and time of event

Date: CPRDay, # (DD-MMM-YYYY) Time: CPRTIME, \$ (HHMM)

Did chest compressions take place?

ChestComp, # If yes, please record the date and time and reason for chest compressions.

Start Date: ChestCompStartDay, # (DD-MMM-YYYY) Start Time: ChestCompStartTime, \$ (HHMM)

Stop Date: ChestCompStopDay, # (DD-MMM-YYYY) Stop Time: ChestCompStopTime, \$ (HHMM)

If chest compressions were needed, why were they started: ChestCompReason, #

CPR performed: ChestOpenClosed, #

OpenClsd
1 = Open chest
2 = Closed chest

Chest
1=Poor perfusion (i.e. bradycardia, hypotension)
2=Pulselessness

YesNo
1=Yes
0=No

Was defibrillation performed?

Defib, #

Was there return of circulation (ROC)?

ROC, # If yes, was ECMO used to achieve ROC? ECMOTOAchieveROC, #

Was the patient alive 24 hours after CPR event?

Alive24HrsAfterCPR, #

SURGERY (1 of 6)

TOPICC Phase II Surgery during PICU Course:

PudID #

Occurrence #

ItemGroupRepeatKey #

PICUSurg (0/9) BloodGas (0/10) Electro... (0/18) -- Select to Jump --

Title: PICU Surgery General Information

Date and Time of Surgery

Date: SurgDay, # (DD-MMM-YYYY) Time: SurgTime, \$ (HHMM)

Date and Time Patient Arrived in the PICU After Surgery

Date: SurgReturnDay, # (DD-MMM-YYYY) Time: SurgReturnTime, \$ (HHMM)

Surgery Details

Elective or Emergency Surgery? SurgCategory, # AdmStat
 1=Elective
 2=Emergency

Type of Surgery? SurgType, # If "Cardiac" is selected, complete the Cardiac Surgery form.

Name of Surgery? SurgName, \$

What was the nurse to patient ratio for this patient's PICU shift when the patient returned from surgery?

SurgNPR1, #

What was the nurse to patient ratio for this patient's second (next) PICU shift after the patient returned from surgery?

SurgNPR2, #

SurgType

1=Cardiac
 2=Interventional cardiac catheterization
 3=Neurosurgery
 4=Orthopedic
 5=Transplant
 6=Trauma
 7=General surgery
 8=ENT
 90=Other

NPR

1=> 1 nurse : 1 patient
 2=1 nurse : 1 patient
 3=1 nurse : 2 patients
 4=1 nurse : > 2 patients

SURGERY (2 of 6)

TOPICC Phase II Surgery during PICU Course:

PICUSurg (0/9)
BloodGas (0/10)
Electro... (0/18)
-- Select to Jump --

Title: Blood Gas Labs

Instructions: Please record the blood gas values specified below during the time window of 2 hours prior to returning to the PICU once surgery has been completed (e.g. labs drawn in the PACU) to 4 hours post return to the PICU after surgery. Please do not include labs drawn during the time of the surgical procedure. PaO2 MUST be from an arterial specimen.

pH

Lowest pH: SurgLowpH, # (##.##)

Highest pH: SurgHighpH, # (##.##) ☐ Not done SurgpHND, #

PCO2

Highest PCO2: SurgHighPCO2, # (mmHg) ☐ Not done SurgPCO2ND, #

PaO2

Lowest PaO2: SurgLowPaO2, # (mmHg) ☐ Not done SurgPaO2ND, #

arterial only

Ionized Calcium

Lowest Ionized Calcium: SurgLowIonCalcium, # (ng/dL) ☐ Not done SurgIonCalciumND, #

uncorrected for pH

Highest Ionized Calcium: SurgHighIonCalcium, # (ng/dL) ☐ Not done SurgIonCalciumND, #

uncorrected for pH

NotDone
95= Not done

TOPICC Phase II Surgery during PICU Course:

BloodGas (0/10) Electro... (0/18) CBC_Coag (0/14) -- Select to Jump --

Title: Electrolyte Labs

Instructions: Please record the electrolyte values specified below during the time window of 2 hours prior to returning to the PICU once surgery has been completed (e.g. labs drawn in the PACU) to 4 hours post return to the PICU after surgery. Please do not include labs drawn during the operating room period.

Sodium

Lowest Sodium: SurgLowSodium, # (mEq/L)

Highest Sodium: SurgHighSodium, # (mEq/L) ☐ Not done SurgSodiumND, #

Potassium

Highest Potassium: SurgHighPotassium, # (mEq/L) ☐ Not done SurgPotassiumND, #

Blood Urea Nitrogen

Highest BUN: SurgHighBUN, # (mg/dL) ☐ Not done SurgHighBUNND, #

Creatinine

Highest Creatinine: SurgHighCreatinine, # (mg/dL) ☐ Not done SurgCreatinineND, #

Glucose

Lowest Glucose: SurgLowGlucose, # (mg/dL)

Highest Glucose: SurgHighGlucose, # (mg/dL) ☐ Not done SurgGlucoseND, #

Total Serum CO2

Lowest Total Serum CO2: SurgLowCO2, # (mmol/L)

Highest Total Serum CO2: SurgHighCO2, # (mmol/L) ☐ Not done SurgCO2ND, #

Total Calcium

Lowest Total Calcium: SurgLowTotalCalcium, # (mmol/L)

Highest Total Calcium: SurgHighTotalCalcium, # (mmol/L) ☐ Not done SurgTotalCalciumND, #

NotDone
95= Not done

SURGERY (4 of 6)

TOPICC Phase II Surgery during PICU Course:

◀ Electro... (0/18) CBC_Coag (0/14) Vitals (0/8) ▶ -- Select to Jump -- ▼

Title: Complete Blood Count and Coagulation Labs

Instructions: Please record the CBC and coagulation values specified below during the time window of 2 hours prior to returning to the PICU once surgery has been completed (e.g. labs drawn in the PACU) to 4 hours post return to the PICU after surgery. Please do not include labs drawn during the operating room period.

White Blood Cells

Lowest WBC: SurgLowWBC, # (x 10³/uL)

Highest WBC: SurgHighWBC, # (x 10³/uL) ☐ Not done SurgWBCNC, #

Hemoglobin

Lowest Hgb: SurgLowHemoglobin, # (dL)

Highest Hgb: SurgHighHemoglobin, # (dL) ☐ Not done SurgHemoglobinND, #

Platelets

Lowest Platelets: SurgLowPlatelets, # (x 10³/uL) ☐ Not done SurgPlateletsND, #

Prothombin Time

Highest PT: SurgHighPT, # (seconds) ☐ Not done SurgPTND, #

Partial Thromboplastin Time

Highest PTT: SurgHighPTT, # (seconds) ☐ Not done SurgPTTND, #

International Normalized Ratio

Highest INR: SurgHighINR, # (%) ☐ Not done SurgINRND, #

NotDone
95= Not done

TOPICC Phase II Surgery during PICU Course:

CBC_Coag (0/14)		Vitals (0/8)		NeuroAs... (0/7)		-- Select to Jump --	
Title: Vital Measurements							
Instructions: The highest and lowest vital measurement values will be gathered from the vitals taken during 0 to 4 hours post-return to the PICU after completion of a surgical procedure. Please do not include vitals taken during the operating room period.							
Temperature							
Highest Temperature:		SurgHighTemp, #		(^C)		Lowest Temperature: SurgLowTemp, # (^C)	
Respiratory Rate							
Highest Respiratory Rate:		SurgHighRespRate, #		(breaths/min)		Lowest Respiratory Rate: SurgLowRespRate, # (breaths/min)	
Heart Rate							
Highest Heart Rate:		SurgHighHeartRate, #		(bpm)		Lowest Heart Rate: SurgLowHeartRate, # (bpm)	
Systolic Blood Pressure							
Highest Systolic BP:		SurgHighSBP, #		(mmHg)		Lowest Systolic BP: SurgLowSBP, # (mmHg)	

TOPICC Phase II Surgery during PICU Course:

CBC_Coag (0/14) Vitals (0/8) NeuroAs...(0/7) -- Select to Jump --

Title: Neurological Assessments

Instructions: The worst scores are to be obtained during 0 to 4 hours post-return to the PICU after completion of a surgical procedure.

Neurological Injury

Is there reasonable suspicion of possible neurological injury for this patient?

SurgCNSInjury, #

GCS Scores

Please note: The GCS motor and total scores must be obtained from the same assessment. Both scores come from the worst GCS motor score assessment.

Worst Motor Score: SurgGCSWorstMotor, # Worst Total Score: SurgGCSWorstTotal, #

Was the patient intubated at the time of GCS assessment?

SurgGCSIntub, #

Level of consciousness

Worst LOC Status: SurgLOCWorst, #

Pupillary reflexes

Worst pupillary reflexes: SurgPupilWorst, #

Were the worst pupillary reflexes due to the patient being hypothermic below 34 °C?

SurgPupilHypo, #

YesNo
1=Yes
0=No

MotorGCS
1=1 2=2
3=3 4=4
5=5 6=6
93=Unable to assess

LOCWorst
1=No coma
2=Coma (unresponsive)
93=Unable to assess

GCSWorst
3=3 4=4
5=5 6=6
7=7 8=8
9=9 10=10
11=11 12=12
13=13 14=14
15=15 93=Unable to assess

Pupil
1=Both reactive
2=One reactive (>3mm)
3=Both non-reactive (>3mm)
4=Both pupils, 3mm, cannot be scored

CARDIACSURGERY (1 of 2)

TOPICC Phase II Cardiac Surgery:

PudID #

Occurrence #

ItemGroupRepeatKey #

ORDisVasoDripDrugs1, #

Select to Jump --

Title: Cardiac Surgery

Instructions: This form is to be completed for patients undergoing cardiovascular surgery immediately prior to or following PICU admission.

Date and Time of Cardiac Surgery

Date: CardiacSurgDay, # (DD-MMM-YYYY)

Time: CardiacSurgTime, \$ (HHMM)

When did the cardiac surgery occur?

CardiacSurgOccur, #

Occur

1=Immediately prior to PICU admission
2=During the initial PICU admission

Was cardiopulmonary bypass used?

Bypass, #

If yes, for how long?

BypassTime, # (minutes)

Was aortic cross-clamp required?

CrossClamp, #

If yes, for how long?

CrossClampTime, # (minutes)

Was deep hypothermia with cardiac arrest used?

HypoArrest, INT

If yes, for how long?

HypoArrestTime, # (minutes)

Did an unplanned cardiac arrest occur?

UnplanArrest, #

Was the patient on vasoactive drips at the time of discharge from the operating room?

ORDisVasoDrips, #

If yes, please record the drugs being infused.

Vasoactive drips:
(check all that apply)

- ☐ Dopamine
- ☐ Dobutamine
- ☐ Epinephrine
- ☐ Norepinephrine
- ☐ Milrinone
- ☐ Amrinone
- ☐ Nitroprusside
- ☐ Nitroglycerin
- ☐ Isoproterenol
- ☐ Vasopressin

Was the patient on ECMO at the time of discharge from the operating room?

ORDisECMO, #

Was the patient on VAD at the time of discharge from the operating room?

ORDisVAD, #

Did the chest remain open at the time of discharge from the operating room?

ORDisChestOpen, #

Record the value of the first lactate drawn after arrival in ICU from surgery:

PostSurgLactate, # (mg/dL)

Record the first pH value obtained after arrival in ICU from surgery:

PostSurgpH, # (.#.##)

Upload de-identified cardiac operative report:

Value not provided

Click to upload file

YesNo
1=Yes
0=No

TOPICC Phase II Cardiac Surgery:**Additional / derived variables included in the CARDIACSURGERY dataset:**

Variable	Type	Label	Algorithm / Notes
ORDisVasoDripDrugs1	#	Dopamine	1 = Yes, 0 = No
ORDisVasoDripDrugs2	#	Dobutamine	1 = Yes, 0 = No
ORDisVasoDripDrugs3	#	Epinephrine	1 = Yes, 0 = No
ORDisVasoDripDrugs4	#	Norepinephrine	1 = Yes, 0 = No
ORDisVasoDripDrugs5	#	Milrinone	1 = Yes, 0 = No
ORDisVasoDripDrugs6	#	Amrinone	1 = Yes, 0 = No
ORDisVasoDripDrugs7	#	Nitroglycerin	1 = Yes, 0 = No
ORDisVasoDripDrugs8	#	Nitroglycerin	1 = Yes, 0 = No
ORDisVasoDripDrugs9	#	Isoproterenol	1 = Yes, 0 = No
ORDisVasoDripDrugs10	#	Vasopressin	1 = Yes, 0 = No

CARDIACPROCEDURES (1 of 10)

TOPICC Phase II Cardiac Procedures:

	PudID #	Occurrence #	ItemGroupRepeatKey #
<div style="display: flex; justify-content: space-between; align-items: center;"> Cardiac...(0/6) -- Select to Jump -- </div>			
Title: Cardiac Procedure			
Primary Procedure			
PrimaryProc1, #		PP1List-See page CardiacProcedure_v1.0 (3 of 10)	▼
PrimaryProc2, #		PP2List-See page CardiacProcedure_v1.0 (4 of 10)	
If "Other", Specify	PrimaryProcOt, \$		
Secondary Procedure			
<div style="display: flex; flex-wrap: wrap;"> <div style="width: 50%;"> <input type="checkbox"/> 1 and 1/2 Ventricular repair <input type="checkbox"/> Aneurysm Sinus of Valsalva, repair <input type="checkbox"/> Aneurysm, pulmonary artery, repair <input type="checkbox"/> Aneurysm, ventricular, left, repair <input type="checkbox"/> Aneurysm, ventricular, right, repair <input type="checkbox"/> Aneurysm Aortic, repair <input type="checkbox"/> Anomalous origin of coronary artery from pulmonary artery repair (ALCAPA) <input type="checkbox"/> Anomalous systemic venous connection repair <input type="checkbox"/> Aortic arch repair + VSD repair <input type="checkbox"/> Aortic arch repair <input type="checkbox"/> Aortic dissection repair <input type="checkbox"/> Aortic root replacement, bioprosthetic <input type="checkbox"/> Aortic root replacement, homograft <input type="checkbox"/> Aortic root replacement, mechanical <input type="checkbox"/> Aortic root replacement, valve sparing <input type="checkbox"/> Aortic stenosis, subvalvar, repair <input type="checkbox"/> Aortic stenosis, supraaortic, repair <input type="checkbox"/> Aortic Valve Replacement, bioprosthetic <input type="checkbox"/> Aortic Valve replacement, homograft <input type="checkbox"/> Aortic Valve replacement, mechanical <input type="checkbox"/> Aortic Valvuloplasty <input type="checkbox"/> Aortopexy <input type="checkbox"/> AP window repair <input type="checkbox"/> Arrhythmia surgery – atrial, surgical ablation <input type="checkbox"/> Arrhythmia surgery-ventricular, surgical ablation <input type="checkbox"/> Arterial Switch Procedure (Jantene Procedure) <input type="checkbox"/> Arterial switch procedure + aortic arch or coarctation repair <input type="checkbox"/> Arterial switch procedure and VSD repair <input type="checkbox"/> Arterial switch procedure and VSD repair + aortic arch or coarctation repair <input type="checkbox"/> Atrial septal fenestration <input type="checkbox"/> ASD creation/enlargement <input type="checkbox"/> ASD partial closure <input type="checkbox"/> ASD repair, patch + PAPVC repair <input type="checkbox"/> ASD repair, patch <input type="checkbox"/> ASD repair, primary suture closure (no patch) </div> <div style="width: 50%;"> <input type="checkbox"/> Glenn (unidirectional cavopulmonary anastomosis; unidirectional Glenn procedure) <input type="checkbox"/> Glenn (unidirectional cavopulmonary anastomosis; unidirectional Glenn procedure) + PA reconstruction <input type="checkbox"/> Hemi-Fontan procedure <input type="checkbox"/> HLHS biventricular repair <input type="checkbox"/> HLHS Hybrid Stage 1 procedure <input type="checkbox"/> HLHS Hybrid Stage 2 procedure <input type="checkbox"/> ICD (AICD) implantation <input type="checkbox"/> ICD (AICD) procedure <input type="checkbox"/> Interrupted aortic arch repair and VSD repair <input type="checkbox"/> Interrupted aortic arch repair <input type="checkbox"/> Konno procedure <input type="checkbox"/> Ligation, pulmonary artery <input type="checkbox"/> LV to aorta tunnel repair <input type="checkbox"/> Mitral stenosis, supraaortic mitral ring repair <input type="checkbox"/> Mitral Valve Replacement <input type="checkbox"/> Mitral Valvuloplasty <input type="checkbox"/> Mustard procedure <input type="checkbox"/> Norwood procedure Sano Modification (using RV to PA shunt) <input type="checkbox"/> Norwood procedure using arterial to pulmonary shunt (modified BT shunt, central shunt) <input type="checkbox"/> Occlusion MAPCA(s) Coarctation repair + VSD repair <input type="checkbox"/> PA banding <input type="checkbox"/> PA debanding <input type="checkbox"/> PA, reconstruction (plasty), branch, central (within the hilar bifurcation) <input type="checkbox"/> PA, reconstruction (plasty), branch, peripheral (at or beyond the hilar bifurcation) <input type="checkbox"/> Pacemaker implantation, permanent <input type="checkbox"/> Pacemaker procedure <input type="checkbox"/> PAPVC, scimitar, repair <input type="checkbox"/> Partial anomalous pulmonary venous connection repair (without ASD) <input type="checkbox"/> Partial left ventriculectomy (LV volume reduction surgery; Batista) <input type="checkbox"/> Patent Ductus Arteriosus ligation (not as part of another procedure) <input type="checkbox"/> Pericardial drainage procedure <input type="checkbox"/> Pericardiectomy <input type="checkbox"/> PFO, primary closure <input type="checkbox"/> Pulmonary artery original from ascending aorta (hemitruncus) repair <input type="checkbox"/> Pulmonary artery sling repair </div> </div>			

CARDIACPROCEDURES (2 of 10)

TOPICC Phase II Cardiac Procedures:

- | | |
|---|--|
| <ul style="list-style-type: none"> <input type="checkbox"/> ASD, common atrium (single atrium), separation <input type="checkbox"/> Atrial baffle procedure (non-Mustard, non-Senning) <input type="checkbox"/> Atrial fenestration closure <input type="checkbox"/> Atrioventricular canal (atrioventricular septal) defect repair <input type="checkbox"/> Atrioventricular canal (atrioventricular septal) defect repair, intermediate (transitional) <input type="checkbox"/> Atrioventricular canal (atrioventricular septal) defect repair, partial (incomplete) PAVSD, primum ASD with cleft Mitral valve <input type="checkbox"/> Bidirectional cavopulmonary anastomosis (bidirectional Glenn procedure) <input type="checkbox"/> Bilateral bidirectional cavopulmonary anastomosis (bilateral bidirectional Glenn procedure) <input type="checkbox"/> Cardiac Assist Device, Ventricular assist device, Implantation <input type="checkbox"/> Cardiac tumor resection <input type="checkbox"/> Coarctation repair, end to end <input type="checkbox"/> Coarctation repair, end to end, extended <input type="checkbox"/> Coarctation repair, interposition graft <input type="checkbox"/> Coarctation repair, patch aortoplasty <input type="checkbox"/> Coarctation repair, subclavian flap <input type="checkbox"/> Coarctation repair + VSD repair <input type="checkbox"/> Conduit placement, LV to PA <input type="checkbox"/> Conduit placement, RV to PA <input type="checkbox"/> Conduit placement, ventricle to aorta <input type="checkbox"/> Conduit replacement, other <input type="checkbox"/> Conduit replacement, RV to PA <input type="checkbox"/> Congenitally corrected TGA repair, arial switch and Rastelli operation <input type="checkbox"/> Congenitally corrected TGA repair, VSD closure <input type="checkbox"/> Congenitally corrected TGA repair, arial switch and ASD (double switch) <input type="checkbox"/> Congenitally corrected TGA repair, VSD closure and LV to PA conduit <input type="checkbox"/> Cor triatriatum repair <input type="checkbox"/> Coronary artery bypass <input type="checkbox"/> Coronary artery fistula ligation <input type="checkbox"/> Coronary surgery other <input type="checkbox"/> Damus-Kaye-Stansel procedure (creation of AP anastomosis without arch reconstruction) <input type="checkbox"/> DOLV repair <input type="checkbox"/> DORV, intraventricular tunnel repair (without RV to PA conduit or arterial switch) <input type="checkbox"/> Double chamber RV repair <input type="checkbox"/> Ebstein's repair <input type="checkbox"/> Fontan revision or conversion (redo Fontan procedure) <input type="checkbox"/> Fontan, atriopulmonary connection <input type="checkbox"/> Fontan, atrioventricular connection <input type="checkbox"/> Fontan, Total cavopulmonary connection, extracardiac conduit, fenestrated <input type="checkbox"/> Fontan, Total cavopulmonary connection, extracardiac conduit, nonfenestrated <input type="checkbox"/> Fontan, total cavopulmonary connection, lateral tunnel, fenestrated <input type="checkbox"/> Fontan, total cavopulmonary connection, lateral tunnel, nonfenestrated | <ul style="list-style-type: none"> <input type="checkbox"/> Pulmonary atresia-VSD (including TOF, PA) repair <input type="checkbox"/> Pulmonary atresia-VSD-MAPCA (pseudotruncus) repair <input type="checkbox"/> Pulmonary embolectomy <input type="checkbox"/> Pulmonary embolectomy, acute pulmonary embolus <input type="checkbox"/> Pulmonary Valve Replacement <input type="checkbox"/> Pulmonary venous stenosis repair <input type="checkbox"/> Pulmonic Valvuloplasty <input type="checkbox"/> Rastelli operation (intracardiac baffle LV to aorta + RV to PA conduit) <input type="checkbox"/> REV (reparation a l'etage ventriculaire) <input type="checkbox"/> Ross procedure <input type="checkbox"/> Ross-Konno procedure <input type="checkbox"/> RVOT procedure <input type="checkbox"/> Senning procedure <input type="checkbox"/> Shunt, ligation and takedown <input type="checkbox"/> Shunt, systemic to pulmonary, central (from aorta or to main pulmonary artery) <input type="checkbox"/> Shunt, systemic to pulmonary, Modified BT shunt, modified Blalock-taussig shunt <input type="checkbox"/> Systemic venous stenosis repair <input type="checkbox"/> TOF repair, ventriculotomy (RV incision), nontransannular patch <input type="checkbox"/> TOF repair, no ventriculotomy (no RV incision) <input type="checkbox"/> TOF repair, RV-PA conduit <input type="checkbox"/> TOF repair, ventriculotomy (RV incision), transannular patch <input type="checkbox"/> TOF-absent pulmonary valve repair <input type="checkbox"/> TOF-AVC (AVSD) repair <input type="checkbox"/> Total anomalous pulmonary venous connection repair Type 1 (Supracardiac) <input type="checkbox"/> Total anomalous pulmonary venous connection repair Type 2 (Cardiac) <input type="checkbox"/> Total anomalous pulmonary venous connection repair Type 3 (Infracardiac) <input type="checkbox"/> Total anomalous pulmonary venous connection repair Type 4 (Mixed) <input type="checkbox"/> Transplantation, heart and lung <input type="checkbox"/> Transplantation, heart <input type="checkbox"/> Transplantation, lung(s) <input type="checkbox"/> Tricuspid Valve Replacement <input type="checkbox"/> Tricuspid Valvuloplasty <input type="checkbox"/> Truncal Valve Valvuloplasty <input type="checkbox"/> Truncus arteriosus + IAA repair <input type="checkbox"/> Truncus arteriosus repair <input type="checkbox"/> Unifocalization MAPCA(s) <input type="checkbox"/> Valve closure, tricuspid (exclusion, univentricular approach) <input type="checkbox"/> Valve excision, tricuspid (without replacement) <input type="checkbox"/> Valve replacement, truncal valve <input type="checkbox"/> Vascular ring repair <input type="checkbox"/> Ventricular septal fenestration <input type="checkbox"/> VSD creation/enlargement <input type="checkbox"/> VSD repair + ASD repair <input type="checkbox"/> VSD repair, patch <input type="checkbox"/> VSD repair, primary stitch closure <input type="checkbox"/> Other |
|---|--|

If "Other", Specify: SecondProcOt, \$

TOPICC Phase II Cardiac Procedures:

PP1List and SP1List

- 1=1 and 1/2 Ventricular repair
- 2=aneurysm Sinus of Valsalva, repair
- 3=Aneurysm, pulmonary artery, repair
- 4=Aneurysm, ventricular, left, repair,
- 5=Aneurysm, ventricular, right, repair
- 6=Aneurysm Aortic, repair
- 7=Anomalous origin of coronary artery from pulmonary artery repair (ALCAPA)
- 8=Anomalous systemic venous connection repair
- 9=Aortic arch repair + VSD repair
- 10=Aortic arch repair
- 11=Aortic dissection repair
- 12=Aortic root replacement, bioprosthetic
- 13=Aortic root replacement, homograft
- 14=Aortic root replacement, mechanical
- 15=Aortic root replacement, valve sparing
- 16=Aortic stenosis, subvalvar, repair
- 17=Aortic stenosis, supravalvar, repair
- 18=Aortic Valve Replacement, bioprosthetic
- 19=Aortic Valve replacement, homograft
- 20=Aortic Valve replacement, mechanical
- 21=Aortic Valvuloplasty
- 22=Aortopexy
- 23=AP window repair
- 24=Arrhythmia surgery – atrial, surgical ablation
- 25=Arrhythmia surgery-ventricular, surgical ablation
- 26=Arterial Switch Procedure (Jantene Procedure)
- 27=Arterial switch procedure + aortic arch or coarctation repair
- 28=Arterial switch procedure and VSD repair
- 29=Arterial switch procedure and VSD repair + aortic arch or coarctation repair
- 30=Artial septal fenestration
- 31=ASD creation/enlargement
- 32=ASD partial closure
- 33=ASD repair, patch + PAPCV repair
- 34=ASD repair, patch,
- 35=ASD repair, primary suture closure (no patch)
- 36=ASD, common atrium (single atrium), separation
- 37=Atrial baffle procedure (non-Mustard, non-Senning)
- 38=Atrial fenestration closure
- 39=Atrioventricular canal (atrioventricular septal) defect repair
- 40=Atrioventricular canal (atrioventricular septal) defect repair, intermediate (transitional)
- 41=Atrioventricular canal (atrioventricular septal) defect repair, partial (incomplete) PAVSD), primum ASD with cleft Mitral valve
- 42=Bidirectional cavopulmonary anastomosis (bidirectional Glenn procedure)
- 43=Bilateral bidirectional cavopulmonary anastomosis (bilateral bidirectional Glenn procedure)
- 44=Cardiac Assist Device, Ventricular assist device, Implantation
- 45=Cardiac tumor resection
- 46=Coarctation repair, end to end
- 47=Coarctation repair, end to end, extended
- 48=Coarctation repair, interposition graft
- 49=Coarctation repair, patch aortoplasty
- 50=Coarctation repair, subclavian flap
- 51=Coarctation repair+ VSD repair
- 52=Conduit placement, LV to PA
- 53=Conduit placement, RV to PA
- 54=Conduit placement, ventricle to aorta
- 55=Conduit replacement, other
- 56=Conduit replacement, RV to PA
- 57=Congenitally corrected TGA repair, artial switch and Rastelli operation
- 58=Congenitally corrected TGA repair, VSD closure
- 59=Congenitally corrected TGA repair, artial switch and ASO (double switch)
- 60=Congenitally corrected TGA repair, VSD closure and LV to PA conduit
- 61=Cor triatriatum repair
- 63=Coronary artery fistula ligation
- 65=Damus-Kaye-Stansel procedure (creation of AP anastomosis without arch reconstruction)
- 67=DORV, intraventricular tunnel repair, (without RV to PA conduit or arterial switch)
- 69=Ebstein's repair
- 71=Fontan, atriopulmonary connection
- 73=Fontan, Total cavopulmonary connection, extracardiac conduit, fenestrated
- 75=Fontan, total cavopulmonary connection, lateral tunnel, fenestrated
- 62=Coronary artery bypass
- 64=Coronary surgery other
- 66=DOLV repair
- 68=Double chamber RV repair
- 70=Fontan revision or conversion (redo Fontan procedure)
- 72=Fontan, atrioventricular connection
- 74=Fontan, Total cavopulmonary connection, extracardiac conduit, nonfenestrated
- 76=Fontan, total cavopulmonary connection, lateral tunnel, nonfenestrated

CARDIACPROCEDURES (4 of 10)

PP2List and SP2List

77=Glenn (unidirectional cavopulmonary anastomosis; unidirectional Glenn procedure)
 78=Glenn (unidirectional cavopulmonary anastomosis; unidirectional Glenn procedure)+ PA reconstruction
 79=Hemi-Fontan procedure
 80=HLHS biventricular repair
 81=HLHS Hybrid Stage 1 procedure
 82=HLHS Hybrid Stage 2 procedure
 83=ICD (AICD) implantation
 84=ICD (AICD) procedure
 85=Interrupted aortic arch repair and VSD repair
 86=Interrupted aortic arch repair
 87=Konno procedure
 88=Ligation, pulmonary artery
 89=LV to aorta tunnel repair
 90=Mitral stenosis, supravalvar mitral ring repair
 91=Mitral Valve Replacement
 92=Mitral Valvuloplasty
 93=Mustard procedure
 94=Norwood procedure Sano Modification (using RV to PA shunt)
 95=Norwood procedure using arterial to pulmonary shunt (modified BT shunt, central shunt)
 96=Occlusion MAPCA(s) Coarctation repair + VSD repair
 97=PA banding
 98=PA debanding
 99=PA, reconstruction (plasty), branch, central (within the hilar bifurcation)
 100=PA, reconstruction (plasty), branch, peripheral (at or beyond the hilar bifurcation)
 101=Pacemaker implantation, permanent
 102=Pacemaker procedure
 103=PAPVC, scimitar, repair
 104=Partial anomalous pulmonary venous connection repair (without ASD)
 105=Partial left ventriculectomy (LV volume reduction surgery; Batista)
 106=Patent Ductus Arteriosus ligation (not as part of another procedure)
 107=Pericardial drainage procedure
 108=Pericardiectomy
 109=PFO, primary closure
 110=Pulmonary artery original from ascending aorta (hemitruncus) repair
 111=Pulmonary artery sling repair
 112=Pulmonary atresia-VSD (including TOF, PA) repair
 113=Pulmonary atresia-VSD-MAPCA (pseudotruncus) repair
 114=Pulmonary embolectomy
 115=Pulmonary embolectomy, acute pulmonary embolus
 116=Pulmonary Valve Replacement
 117=Pulmonary venous stenosis repair
 118=Pulmonic Valvuloplasty
 119=Rastelli operation, (intracardiac baffle LV to aorta + RV to PA conduit)
 120=REV (reparation a l'etage ventriculaire)
 121=Ross procedure
 122=Ross-Konno procedure
 123=RVOT procedure
 124=Senning procedure
 125=Shunt, ligation and takedown
 126=Shunt, systemic to pulmonary, central (from aorta or to main pulmonary artery)
 127=Shunt, systemic to pulmonary, Modified BT shunt, modified Blalock-taussig shunt
 128=Systemic venous stenosis repair
 129=TOF repair, ventriculotomy (RV incision), nontransannular patch
 130=TOF repair, no ventriculotomy (no RV incision)
 131=TOF repair, RV-PA conduit
 132=TOF repair, ventriculotomy (RV incision), transannular patch
 133=TOF-absent pulmonary valve repair
 134=TOF-AVC (AVSD) repair
 135=Total anomalous pulmonary venous connection repair Type 1 (Supracardiac)
 136=Total anomalous pulmonary venous connection repair Type 2 (Cardiac)
 137=Total anomalous pulmonary venous connection repair Type 3 (Infracardiac)
 138=Total anomalous pulmonary venous connection repair Type 4 (Mixed)
 139=Transplantation, heart and lung
 141=Transplantation, lung(s)
 143=Tricuspid Valvuloplasty
 145=Truncus arteriosus + IAA repair
 147=Unifocalization MAPCA(s)
 149=Valve excision, tricuspid (without replacement)
 151=Vascular ring repair
 153=VSD creation/enlargement
 155=VSD repair, patch
 157=Other

140=Transplantation, heart
 142=Tricuspid Valve Replacement
 144=Truncal Valve Valvuloplasty
 146=Truncus arteriosus repair
 148=Valve closure, tricuspid (exclusion, univentricular approach)
 150=Valve replacement, truncal valve
 152=Ventricular septal fenestration
 154=VSD repair + ASD repair
 156=VSD repair, primary stitch closure

TOPICC Phase II Cardiac Procedures:**Additional / derived variables included in the CARDIACPROCEDURES dataset:**

Variable	Type	Label	Algorithm / Notes
SecondProc11	#	1 and 1/2 Ventricular repair	1 = Yes, 0 = No
SecondProc12	#	Aneurysm Sinus of Valsalva; repair	1 = Yes, 0 = No
SecondProc13	#	Aneurysm; pulmonary artery; repair	1 = Yes, 0 = No
SecondProc14	#	Aneurysm; ventricular; left; repair	1 = Yes, 0 = No
SecondProc15	#	Aneurysm; ventricular; right; repair	1 = Yes, 0 = No
SecondProc16	#	Aneurysm Aortic; repair	1 = Yes, 0 = No
SecondProc17	#	Anomalous origin of coronary artery from pulmonary artery repair (ALCAPA)	1 = Yes, 0 = No
SecondProc18	#	Anomalous systemic venous connection repair	1 = Yes, 0 = No
SecondProc19	#	Aortic arch repair + VSD repair	1 = Yes, 0 = No
SecondProc110	#	Aortic arch repair	1 = Yes, 0 = No
SecondProc111	#	Dissection repair	1 = Yes, 0 = No
SecondProc112	#	Aortic root replacement; bioprosthetic	1 = Yes, 0 = No
SecondProc113	#	Aortic root replacement; homograft	1 = Yes, 0 = No
SecondProc114	#	Aortic root replacement; mechanical	1 = Yes, 0 = No
SecondProc115	#	Aortic root replacement; valve sparing	1 = Yes, 0 = No
SecondProc116	#	Aortic stenosis; subvalvar; repair	1 = Yes, 0 = No
SecondProc117	#	Aortic stenosis; supravalvar; repair	1 = Yes, 0 = No
SecondProc118	#	Aortic Valve Replacement; bioprosthetic	1 = Yes, 0 = No
SecondProc119	#	Aortic Valve replacement; homograft	1 = Yes, 0 = No
SecondProc120	#	Aortic Valve replacement; mechanical	1 = Yes, 0 = No
SecondProc121	#	Aortic Valvuloplasty	1 = Yes, 0 = No
SecondProc122	#	Aortopexy	1 = Yes, 0 = No
SecondProc123	#	AP window repair	1 = Yes, 0 = No
SecondProc124	#	Arrhythmia surgery – atrial; surgical ablation	1 = Yes, 0 = No
SecondProc125	#	Arrhythmia surgery-ventricular; surgical ablation	1 = Yes, 0 = No
SecondProc126	#	Arterial Switch Procedure (Jantene Procedure)	1 = Yes, 0 = No
SecondProc127	#	Arterial switch procedure + aortic arch or coarctation repair	1 = Yes, 0 = No
SecondProc128	#	Arterial switch procedure and VSD repair	1 = Yes, 0 = No

TOPICC Phase II Cardiac Procedures:**Additional / derived variables included in the CARDIACPROCEDURES dataset:**

Variable	Type	Label	Algorithm / Notes
SecondProc129	#	Arterial switch procedure and VSD repair + aortic arch or coarctation repair	1 = Yes, 0 = No
SecondProc130	#	Artial septal fenestration	1 = Yes, 0 = No
SecondProc131	#	ASD creation/enlargement	1 = Yes, 0 = No
SecondProc132	#	ASD partial closure	1 = Yes, 0 = No
SecondProc133	#	ASD repair; patch + PAPCV repair	1 = Yes, 0 = No
SecondProc134	#	ASD repair; patch	1 = Yes, 0 = No
SecondProc135	#	ASD repair; primary suture closure (no patch)	1 = Yes, 0 = No
SecondProc136	#	ASD; common atrium (single atrium); separation	1 = Yes, 0 = No
SecondProc137	#	Atrial baffle procedure (non-Mustard; non-Senning)	1 = Yes, 0 = No
SecondProc138	#	Atrial fenestration closure	1 = Yes, 0 = No
SecondProc139	#	Atrioventricular canal (atrioventricular septal) defect repair	1 = Yes, 0 = No
SecondProc140	#	Atrioventricular canal (atrioventricular septal) defect repair; intermediate (transitional)	1 = Yes, 0 = No
SecondProc141	#	Atrioventricular canal (atrioventricular septal) defect repair; partial (incomplete PAVSD); primum ASD with cleft Mitral valve	1 = Yes, 0 = No
SecondProc142	#	Bidirectional cavopulmonary anastomosis (bidirectional Glenn procedure)	1 = Yes, 0 = No
SecondProc143	#	Bilateral bidirectional cavopulmonary anastomosis (bilateral bidirectional Glenn procedure)	1 = Yes, 0 = No
SecondProc144	#	Cardiac Assist Device; Ventricular assist device; Implantation	1 = Yes, 0 = No
SecondProc146	#	Cardiac tumor resection	1 = Yes, 0 = No
SecondProc147	#	Coarctation repair; end to end; extended	1 = Yes, 0 = No
SecondProc148	#	Coarctation repair; interposition graft	1 = Yes, 0 = No
SecondProc149	#	Coarctation repair; patch aortoplasty	1 = Yes, 0 = No
SecondProc150	#	Coarctation repair; subclavian flap	1 = Yes, 0 = No
SecondProc151	#	Coarctation repair+ VSD repair	1 = Yes, 0 = No
SecondProc152	#	Conduit placement; LV to PA	1 = Yes, 0 = No
SecondProc153	#	Conduit placement; RV to PA	1 = Yes, 0 = No
SecondProc154	#	Conduit placement; ventricle to aorta	1 = Yes, 0 = No

TOPICC Phase II Cardiac Procedures:**Additional / derived variables included in the CARDIACPROCEDURES dataset:**

Variable	Type	Label	Algorithm / Notes
SecondProc155	#	Conduit replacement; other	1 = Yes, 0 = No
SecondProc156	#	Conduit replacement; RV to PA	1 = Yes, 0 = No
SecondProc157	#	Congenitally corrected TGA repair; arial switch and Rastelli operation	1 = Yes, 0 = No
SecondProc158	#	Congenitally corrected TGA repair; VSD closure	1 = Yes, 0 = No
SecondProc159	#	Congentially corrected TGA repair; artial switch and ASO (double switch)	1 = Yes, 0 = No
SecondProc160	#	Congentially corrected TGA repair; VSD closure and LV to PA conduit	1 = Yes, 0 = No
SecondProc161	#	Cor triatriatum repair	1 = Yes, 0 = No
SecondProc162	#	Coronary artery bypass	1 = Yes, 0 = No
SecondProc163	#	Coronary artery fistula ligation	1 = Yes, 0 = No
SecondProc164	#	Coronary surgery other	1 = Yes, 0 = No
SecondProc165	#	Damus-Kaye-Stansel procedure (creation of AP anastomosis without arch reconstruction)	1 = Yes, 0 = No
SecondProc166	#	DOLV repair	1 = Yes, 0 = No
SecondProc167	#	DORV; intraventricular tunnel repair (without RV to PA conduit or arterial switch)	1 = Yes, 0 = No
SecondProc168	#	Double chamber RV repair	1 = Yes, 0 = No
SecondProc169	#	Ebstein's repair	1 = Yes, 0 = No
SecondProc170	#	Fontan revision or conversion (redo Fontan procedure)	1 = Yes, 0 = No
SecondProc171	#	Fontan; atriopulmonary connection	1 = Yes, 0 = No
SecondProc172	#	Fontan; atrioventricular connection	1 = Yes, 0 = No
SecondProc173	#	Fontan; Total cavopulmonary connection; extracardiac conduit; fenestrated	1 = Yes, 0 = No
SecondProc174	#	Fontan; Total cavopulmonary connection; extracardiac conduit; nonfenestrated	1 = Yes, 0 = No
SecondProc175	#	Fontan; total cavopulmonary connection; lateral tunnel; fenestrated	1 = Yes, 0 = No
SecondProc176	#	Fontan; total cavopulmonary connection; lateral tunnel; nonfenestrated	1 = Yes, 0 = No
SecondProc277	#	Glenn (unidirectional cavopulmonary anastomosis; unidirectional Glenn procedure)	1 = Yes, 0 = No

TOPICC Phase II Cardiac Procedures:**Additional / derived variables included in the CARDIACPROCEDURES dataset:**

Variable	Type	Label	Algorithm / Notes
SecondProc278	#	Glenn (unidirectional cavopulmonary anastomosis; unidirectional Glenn procedure)+ PA reconstruction	1 = Yes, 0 = No
SecondProc279	#	Hemi-Fontan procedure	1 = Yes, 0 = No
SecondProc280	#	HLHS biventricular repair	1 = Yes, 0 = No
SecondProc281	#	HLHS Hybrid Stage procedure	1 = Yes, 0 = No
SecondProc282	#	HLHS Hybrid Stage 2 procedure	1 = Yes, 0 = No
SecondProc283	#	ICD (AICD) implantation	1 = Yes, 0 = No
SecondProc284	#	ICD (AICD) procedure	1 = Yes, 0 = No
SecondProc285	#	Interrupted aortic arch repair and VSD repair	1 = Yes, 0 = No
SecondProc286	#	Interrupted aortic arch repair	1 = Yes, 0 = No
SecondProc287	#	Konno procedure	1 = Yes, 0 = No
SecondProc288	#	Ligation; pulmonary artery	1 = Yes, 0 = No
SecondProc289	#	LV to aorta tunnel repair	1 = Yes, 0 = No
SecondProc290	#	Mitral stenosis; supravalvar mitral ring repair	1 = Yes, 0 = No
SecondProc291	#	Mitral Valve Replacement	1 = Yes, 0 = No
SecondProc292	#	Mitral Valvuloplasty	1 = Yes, 0 = No
SecondProc293	#	Mustard procedure	1 = Yes, 0 = No
SecondProc294	#	Norwood procedure Sano Modification (using RV to PA shunt)	1 = Yes, 0 = No
SecondProc295	#	Norwood procedure using arterial to pulmonary shunt (modified BT shunt; central shunt)	1 = Yes, 0 = No
SecondProc296	#	Occlusion MAPCA(s) Coarctation repair + VSD repair	1 = Yes, 0 = No
SecondProc297	#	PA banding	1 = Yes, 0 = No
SecondProc298	#	PA debanding	1 = Yes, 0 = No
SecondProc299	#	PA; reconstruction (plasty); branch; central (within the hilar bifurcation)	1 = Yes, 0 = No
SecondProc2100	#	PA; reconstruction (plasty); branch; peripheral (at or beyond the hilar bifurcation)	1 = Yes, 0 = No
SecondProc2101	#	Pacemaker implantation; permanent	1 = Yes, 0 = No
SecondProc2102	#	Pacemaker procedure	1 = Yes, 0 = No

TOPICC Phase II Cardiac Procedures:**Additional / derived variables included in the CARDIACPROCEDURES dataset:**

Variable	Type	Label	Algorithm / Notes
SecondProc2103	#	PAPVC; scimitar; repair	1 = Yes, 0 = No
SecondProc2104	#	Partial anomalous pulmonary venous connection repair (without ASD)	1 = Yes, 0 = No
SecondProc2105	#	Partial left ventriculectomy (LV volume reduction surgery; Batista)	1 = Yes, 0 = No
SecondProc2106	#	Patent Ductus Arteriosus ligation (not as part of another procedure)	1 = Yes, 0 = No
SecondProc2107	#	Pericardial drainage procedure	1 = Yes, 0 = No
SecondProc2108	#	Pericardiectomy	1 = Yes, 0 = No
SecondProc2109	#	PFO; primary closure	1 = Yes, 0 = No
SecondProc2110	#	Pulmonary artery original from ascending aorta (hemitruncus) repair	1 = Yes, 0 = No
SecondProc2111	#	Pulmonary artery sling repair	1 = Yes, 0 = No
SecondProc2112	#	Pulmonary atresia-VSD (including TOF; PA) repair	1 = Yes, 0 = No
SecondProc2113	#	Pulmonary atresia-VSD-MAPCA (pseudotruncus) repair	1 = Yes, 0 = No
SecondProc2114	#	Pulmonary embolectomy	1 = Yes, 0 = No
SecondProc2115	#	Pulmonary embolectomy; acute pulmonary embolus	1 = Yes, 0 = No
SecondProc2116	#	Pulmonary Valve Replacement	1 = Yes, 0 = No
SecondProc2117	#	Pulmonary venous stenosis repair	1 = Yes, 0 = No
SecondProc2118	#	Pulmonic Valvuloplasty	1 = Yes, 0 = No
SecondProc2119	#	Rastelli operation (intracardiac baffle LV to aorta + RV to PA conduit)	1 = Yes, 0 = No
SecondProc2120	#	REV (reparation a letage ventriculaire)	1 = Yes, 0 = No
SecondProc2121	#	Ross procedure	1 = Yes, 0 = No
SecondProc2122	#	Ross-Konno procedure	1 = Yes, 0 = No
SecondProc2123	#	RVOT procedure	1 = Yes, 0 = No
SecondProc2124	#	Senning procedure	1 = Yes, 0 = No
SecondProc2125	#	Shunt; ligation and takedown	1 = Yes, 0 = No
SecondProc2126	#	Shunt; systemic to pulmonary; central (from aorta or to main pulmonary artery)	1 = Yes, 0 = No
SecondProc2127	#	Shunt; systemic to pulmonary; Modified BT shunt; modified Blalock-taussig shunt	1 = Yes, 0 = No
SecondProc2128	#	Systemic venous stenosis repair	1 = Yes, 0 = No
SecondProc2129	#	TOF repair; ventriculotomy (RV incision); nontransanular patch	1 = Yes, 0 = No

TOPICC Phase II Cardiac Procedures:**Additional / derived variables included in the CARDIACPROCEDURES dataset:**

Variable	Type	Label	Algorithm / Notes
SecondProc2130	#	TOF repair; no ventriculotomy (no RV incision)	1 = Yes, 0 = No
SecondProc2131	#	TOF repair; RV-PA conduit	1 = Yes, 0 = No
SecondProc2132	#	TOF repair; ventriculotomy (RV incision); transannular patch	1 = Yes, 0 = No
SecondProc2133	#	TOF-absent pulmonary valve repair	1 = Yes, 0 = No
SecondProc2134	#	TOF-AVC (AVSD) repair	1 = Yes, 0 = No
SecondProc2135	#	Total anomalous pulmonary venous connection repair Type 1 (Supracardiac)	1 = Yes, 0 = No
SecondProc2136	#	Total anomalous pulmonary venous connection repair Type 2 (Cardiac)	1 = Yes, 0 = No
SecondProc2137	#	Total anomalous pulmonary venous connection repair Type 3 (Infracardiac)	1 = Yes, 0 = No
SecondProc2138	#	Total anomalous pulmonary venous connection repair Type 4 (Mixed)	1 = Yes, 0 = No
SecondProc2139	#	Transplantation; heart and lung	1 = Yes, 0 = No
SecondProc2140	#	Transplantation; heart	1 = Yes, 0 = No
SecondProc2141	#	Transplantation; lung(s)	1 = Yes, 0 = No
SecondProc2142	#	Tricuspid Valve Replacement	1 = Yes, 0 = No
SecondProc2143	#	Tricuspid Valvuloplasty	1 = Yes, 0 = No
SecondProc2144	#	Truncal Valve Valvuloplasty	1 = Yes, 0 = No
SecondProc2145	#	Truncus arteriosus + IAA repair	1 = Yes, 0 = No
SecondProc2146	#	Truncus arteriosus repair	1 = Yes, 0 = No
SecondProc2147	#	Unifocalization MAPCA(s)	1 = Yes, 0 = No
SecondProc2148	#	Valve closure; tricuspid (exclusion; univentricular approach)	1 = Yes, 0 = No
SecondProc2149	#	Valve excision; tricuspid (without replacement)	1 = Yes, 0 = No
SecondProc2150	#	Valve replacement; truncal valve	1 = Yes, 0 = No
SecondProc2151	#	Vascular ring repair	1 = Yes, 0 = No
SecondProc2152	#	Ventricular septal fenestration	1 = Yes, 0 = No
SecondProc2153	#	VSD creation/enlargement	1 = Yes, 0 = No
SecondProc2154	#	VSD repair + ASD repair	1 = Yes, 0 = No
SecondProc2155	#	VSD repair; patch	1 = Yes, 0 = No
SecondProc2156	#	VSD repair; primary stitch closure	1 = Yes, 0 = No
SecondProc2157	#	Other	1 = Yes, 0 = No

CATASTROPHICEVENTS (1 of 1)

TOPICC Phase II Catastrophic Events during Hospitalization:

PudID #

Occurrence #

ItemGroupRepeatKey #

◀ Catastr...(0/4) ▶ -- Select to Jump -- ▼

Title: Catastrophic Events during Hospitalization				
Date (DD-MMM-YYYY)	Time (HHMM)	Catastrophic Event	Other (specify)	
HospCEDay, #	HospCETime, \$	HospCEDesc, #	HospCEDescOther, \$	X
ADD				

Event
 1=Hypoxic Ischemic Encephalopathy
 2=Cardiac Arrest
 3=Respiratory Arrest
 4=Traumatic Brain Injury
 5=Spinal Cord Injury
 6=Stroke
 90=Other

DEATH (1 of 2)

TOPICC Phase II Hospital Death:

PudID #

Occurrence #

ItemGroupRepeatKey #

◀ **Death (0/5)** Autopsy (0/5) Organ (0/4) ▶ -- Select to Jump -- ▼

Title: Death Information

Instructions: This information will be collected for those patients dying in the PICU or in the hospital.

Date of Death: DeathDay, # (DD-MMM-YYYY) Time of Death: DeathTime, \$ (HHMM)

Location of Death: DeathLoc, #

Was CPR administered? CPRAdmin, # (1=Yes, 0=No)

Mode of death: DeathMode, #

LocDeath

1=ICU

2=Step-down unit

3=Hospital general care

90=Other

DeathMod

1=Failed resuscitation

2= Withdrawal of care

3=Limitation of care

4=Brain death

◀ **Death (0/5)** **Autopsy (0/5)** Organ (0/4) ▶ -- Select to Jump -- ▼

Title: Autopsy Information

Was this a medical examiner case? MECase, #

Was an autopsy requested? AutopsyRequest, #

Was an autopsy performed? AutopsyDone, # (1=Yes, 0=No)

Depending on your response to this question, answer the appropriate question below.

If an autopsy was performed, where was the autopsy done? AutopsyLoc, #

If an autopsy was not performed, why not? ReasonNoAutopsy, #

Autopsy

1=Medical examiner's office

2=Hospital

90=Other

AutoNull

1=Physician did not offer option of autopsy to parent

2=Physician offered the option of autopsy but parent refused

TOPICC Phase II Hospital Death:

◀ **Death (0/5)** **Autopsy (0/5)** **Organ (0/4)** ▶ -- Select to Jump -- ▼

Title: Organ Donation Information

Was organ donation offered?

DonationOffer, # If yes, please answer the next question.

Did organ donation occur?

DonationOccur, # If yes, please answer the remaining questions on this form.

Organ donation occurred following: DonationFollow, #

DonType
1=Brain death
2=Cardiac death

Organ(s) donated: (check all that apply)

- ☐ Heart
- ☐ Liver
- ☐ Kidneys
- ☐ Pancreas
- ☐ Intestines
- ☐ Other

YesNo
1=Yes
0=No

Additional / derived variables included in the DEATH dataset:

Variable	Type	Label	Algorithm / Notes
DonationOrgan1	#	Heart	1 = Yes, 0 = No
DonationOrgan2	#	Liver	1 = Yes, 0 = No
DonationOrgan3	#	Kidneys	1 = Yes, 0 = No
DonationOrgan4	#	Pancreas	1 = Yes, 0 = No
DonationOrgan5	#	Intestines	1 = Yes, 0 = No
DonationOrgan90	#	Other	1 = Yes, 0 = No

