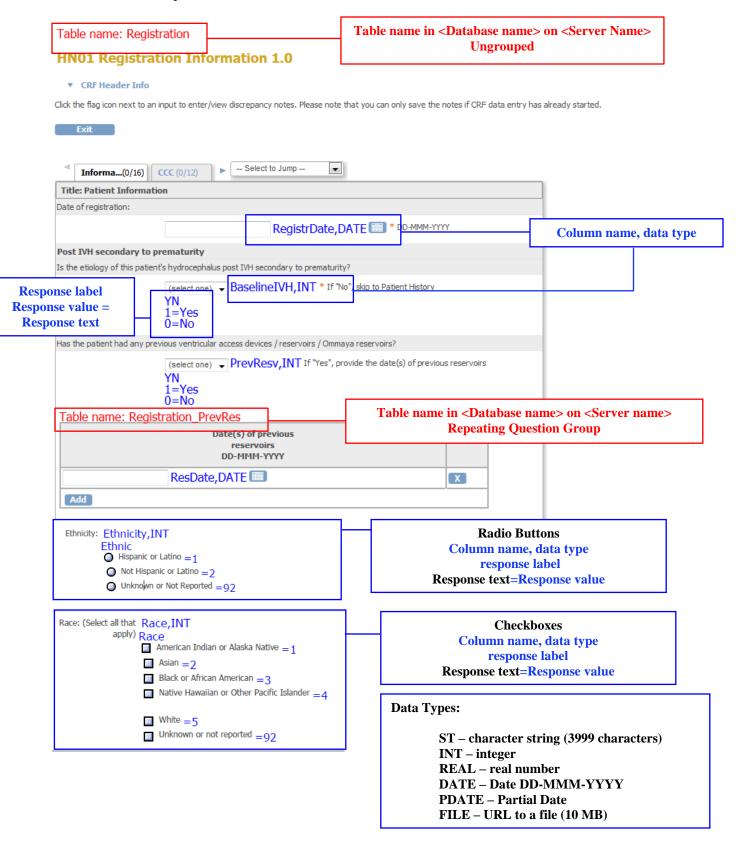
# Public Use Dataset Annotated eCRF

# Life After Pediatric Sepsis LAPSE CPCCRN Protocol Number 053

Collaborative Pediatric Critical Care Research Network

PUD Annotated eCRF Version 1 Version Date: August 22nd, 2019

# **Annotations key:**



#### Notes:

PUDID is a randomly generated ID integer that uniquely identifies a patient across datasets. It does not contain information about original site or medical record number. PUDID, Occurrence, and ItemGroupRepeatKey are unique identifiers in all datasets. Occurrence and ItemGroupRepeatKey are system-generated integer data where Occurrence>0 indicates repeated forms and ItemGroupRepeatKey>0 repeated rows within forms.

The original screening dates of subject study enrollment have been replaced with values of 0 (ScreenDay) for all subjects. Integer values representing the number of days since screening replace all other data elements where dates were collected. Dates occurring before the day of screening have negative integer values.

The public use datasets include data as collected and seldom may include implausible lab values and other questionable data.

Sensitive and/or identifying information entered in free text fields have been removed.

Data elements that were collected as 'check all that apply' were systematically converted to 0,1 indicator variables, e.g. The variable OrganismType is included as OrganismType1, OrganismType2, OrganismType3, and OrganismType4. Corresponding labels and formats are included as tables at the bottom of each CRF.

Title: Inclusion Criteria			
Screening Date:		ScreenDay,INT	
clusion Criteria			
Is the subject = 44 weeks			
	Inclusion1,IN YNr	NI *	
	Yes =1		
	<sup>No</sup> <b>=0</b>		
Is the subject suspected to	o have sepsis / infe	ction (currently receiving antimicrobials	or written orders for identification of a microbial pathogen e.g., blood cultures, PCR, or Gram Stain of a fluid)?
	Inclusion2,IN YNr	<b>NT</b> *	
	Yes =1		
	<sup>No</sup> =0		
Specify the type of Or			
organisht for this			
(coloct all that apply)	Bacterial Fungal		
	Protozoal		refers to the infection information available at the time of eligibility. If later it is determined that the subject has a pe the original information obtained at eligibility. Document the infection information on the Microbiology Results form
	Viral		
Is the bacterial	(select one)	BacterialType,INT	Value not provided
infection:	DocSus		value not provided
	1=Document 2=Suspected	ted 1	
To the former			
Is the fungal infection:	(select one)	FungalType,INT	Value not provided
	1=Documen	ted	
	2=Suspected	1	
Is the protozoal infection:	(001001 0110)	ProtoType,INT	Value not provided
	DocSus 1=Document	ted	
	2=Suspected	1	
Is the viral infection:	(select one)	ViralType,INT	Value not provided
	DocSus 1=Document	tod	
	2=Suspected		
		temic inflammatory response syndrome nite blood cell count or body temperatu	
	Inclusion3,IN		
	YNr		
	<sup>Yes</sup> =1 <sup>No</sup> =0		
Indicate SIRS criteria met at time of	SIRSAtEligib	le	
eligibility (select all that apply)	nypourciniu	(< 36 degrees C) OR Fever (> 38.5 deg	
(second an and apply)	Leukocytosis (		00 mm3) OR > 10% immature neutrophils
		00th percentile for age in absence of sti te > 90th percentile for age OR Hyperv	nulation entilation to PaCO2 < 32 torr OR Requirement for mechanical ventilation unrelated to drug administration
. Does the subject have cor	nmunity acquired ir	nfection or sepsis (diagnosis within 48 h	uurs of hospital admission)?
	Inclusion4,IN		
	YNr		

<sup>No</sup> =0
5. Does the subject have cardiovascular organ dysfunction (requiring vasoactive inotropic infusion)?
Inclusion5,INT * YNr Y <sup>es</sup> = 1

<sup>No</sup> =0

6. Does the subject have pulmonary organ dysfunction (requiring invasive or non-invasive pressure support or mechanical ventilation)?

Variable Name	Label / Description	Values / Format
OrganismType1	Bacterial	1 = Yes, 0 = No
OrganismType2	Fungal	1 = Yes, 0 = No
OrganismType3	Protozoal	1 = Yes, 0 = No
OrganismType4	Viral	1 = Yes, 0 = No
SIRSAtEligible1	Hypothermia (< 36 degrees C) OR Fever (> 38.5 degrees C)	1 = Yes, 0 = No
SIRSAtEligible2	Leukocytosis (> 12k mm3) OR Neutropenia (< 4k mm3) OR > 10 percent	
	immature neutrophils	1 = Yes, 0 = No
SIRSAtEligible3	Heart rate > 90th percentile for age in absence of stimulation	1 = Yes, 0 = No
SIRSAtEligible4	Respiratory rate > 90th percentile for age OR Hyperventilation to PaCO2 < 32 torr OR	
	Requirement for mechanical ventilation unrelated to drug administration	1 = Yes, 0 = No

# LAPSE Eligibility v2.0

Inclusi(0/17) Exclusi(0/14) Select to Jump	)
Title: Exclusion Criteria	
Exclusion Criteria	
1. Is the subject's primary reason for PICU admission a thermal or elec	:trical burn?
Exclusion1,INT *	
YNr <sup>Yes</sup> =1	
No = 0	
	e care as indicated by do not resuscitate orders and/or other limitations of care?
	י כמר מא ווינוכמנפע שא שט ווטר רפשטכונמנפ טועפוא מווע/טו טנויפו ווווונמנטווא טו כמרכי
Exclusion2,INT * YNr	
Yes =1	
<sup>No</sup> =0	
3. Are the parents or guardians of the subject unable to speak English	or Spanish?
Exclusion3,INT *	
YNr	
Yes =1 No =0	
4. Is the subject a ward of the state?	
Exclusion4,INT * YNr	
Yes =1	
<sup>No</sup> =0	
5. Is the subject unable to participate in long term follow-up?	
Exclusion5,INT *	
YNr	
Yes =1	
No =0	
6. Has the subject been previously enrolled in this study?	
Exclusion6,INT * YNr	
Yes =1	
No =0	
7. Was the subject unable to be enrolled in this study within 48 hours	of PICU admission?
Exclusion7v2,INT *	
YNr	
Yes =1	
No =0	
Is subject eligible?	
Eligible subjects have all inclusion criteria marked as Yes, and all exclu	sion criteria marked as No.
Eligible,INT * YNr	
YNr <sup>Yes</sup> =1	
No = 0	
•	
Consent Information Was the parent / guardian approached for consent to participate in thi	is study for their child?
(select one) ApproachConse	יחד, דא ו
YN 1=Yes	
1=Yes 0=No	
Provide the reason parent / guardian was not approached for consent	for their child:
(select one)	NotApproachConsent,INT

NoAprch 1=Attending physician prefers subject not be offered the opportunity to participate in the study 2=Site investigator and/or research coordinator resources inadequate to recruit additional subject 3=Parent(s) / Guardian(s) unavailable to consent 90=Other				
Other (specify):	NotApproachConsentOther,ST			
Did the parent / guardian consent to participa	te in this study for their child?			
(select one) YN 1=Yes 0=No	ConsentGiven,INT If "No", save this page and	do not continue. You have completed data entry for	this subject.	
Consent Day / Time				
Day:	ConsentDay,INT	Time:	ConsentTime,ST (HHMM)	

## LAPSE Hospitalization Summary Form v1.0

Dates (0/14)			
Title: Hospitalization Dates			
Hospital Admission Date and	Time		
Date:	HOSPADMITDAY,	INT Time	HospAdmitTime,ST (HHMM)
PICU Admission Date and Tim	ie		
Date:	PICUADMITDAY	INT Time	PICUAdmitTime,ST (HHMM)
PICU Discharge Information			
Date:	PICUDISDAY, INT	Time:	PICUDisTime,ST (HHMM)
Vital Status at PICU (se Discharge: Vit 1= 0=	elect one) PICUVitalStatus,INT Stat Alive Dead		
Hospital Discharge Information	on		
Date:	HOSPDISDAY, INT	Time:	HospDisTime,ST (HHMM)
Vital Status at Hospital (se Discharge: Vit 1= 0=	elect one) HospVitalStatus,INT Stat Alive Dead		
Death Information			
Date:	DEATHDAY, INT	Time:	DeathTime,ST (HHMM)
Was an autopsy obtained?			
YN 1=	elect one) AutopsyObtain,INT Yes No		
Upload Full Autopsy Report:	Va	lue not provided	

# LAPSE Demographics v1.0

e: Demographics			
Date of birth:	BIRTHDAY, INT	DD-MMM-YYYY)	Sex: Sex, INT MFr Male =
			Female
Ethnicity: Ethnicity,INT Ethnic	(select	Race: Race all that apply)	
Hispanic or La	<sup>tino</sup> =1	American India	n or Alaska Native
Not Hispanic of	r Latino = 2	Asian	
Unknown or N	ot Reported $= 92$	Black or African	n American
		Native Hawaiia	n or Other Pacific Islander
		White	
		Unknown or No	ot Reported

Variable Name	Label / Description	Values / Format
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

#### Table Name: BaseClinical

## LAPSE Baseline Clinical Data v1.0

Title: Baseline Clinical Da	ita			
instructions: The baseline cl soonest thereafter.	inical data should ı	eflect the subject's status during the mo	onth prior to the severe sepsis h	ospitalization. The height and weight are those of Day 0 (Day of PICU admission), or
Date:		BASELINEDAY, INT		
Height at PICU admission:		Height,REAL (cm)	Weight at PICU admission:	Weight, REAL (kg)
/as the subject immunod	ompromised dur	ing the month prior to the severe s	epsis hospitalization?	
	(select one) YN 1=Yes 0=No	Immunocompromised,INT	Note: If yes is marked, a reason	must be indicated below.
immunocompromised, prov	ide reason:			
immunodeficiency?	(select one) YN 1=Yes 0=No	CongenitalImmunodef,INT		
Bone marrow or stem cell transplantation?	(select one) YN 1=Yes 0=No	MarrowTransplant,INT		
Graft versus host disease?	(select one) YNNA 1=Yes 0=No 96=Not appl	GraftHostDisease,INT		
transplantation?	(select one) YN 1=Yes 0=No	OrganTransplant, INT		
	(select one) YN 1=Yes 0=No	Malnutrition,INT		
	(select one) YN 1=Yes 0=No	Malignancy,INT		
Chemotherapy or radiotherapy within last 3 months?	(select one) YN 1=Yes 0=No	Chemotherapy,INT		
Rheumatologic disease?	(select one) YN 1=Yes 0=No	RheumaDisease,INT		
Neutropenia (ANC < 1000 cells/µL)?		Neutropenia,INT		

0	)=No					
Y 1	(select one) (N =Yes )=No	SickleCell,INT				
Systemic steroid use ( (chronic or acute)? Y 1 0	(select one) /N .=Yes )=No	SteroidUse,INT				
immunosuppression? Y	(select one) /N .=Yes )=No	OtherImmuno,INT	Other immunosuppression (specify):	OtherImm	nunoSpecify,ST	

#### LAPSE Functional Assessments v1.0

PCPC/P	O(0/3) FSS (0/6)	Select to Jump					
Title: PCPC/F	Title: PCPC/POPC						
	Date:	PCPCDAY,INT					
Pediatric Cere	bral Performance Cate	egory (PCPC)					
	2 - Mil 3 - Mc 4 - Se 5 - Co	core,INT pormal =1 ild disability =2 oderate disability =3 evere disability =4 pma/vegetative state =5 rain death =6					
Pediatric Over	rall Performance Categ	gory (POPC)					
	2 - Mil 3 - Mc 4 - Se 5 - Co	core,INT bod = 1 ild disability =2 oderate disability =3 evere disability =4 pma/vegetative state =5 rain death =6					

#### LAPSE Baseline Functional Assessments v1.0

<b>PCPC/PO</b> (0/3)	FSS (0/6) Select to Jump	
Title: FSS		
unctional Status Scale (F	SS)	
Mental Status	FSSMental,INT	
Classification:		
	Normal =1	
	Mild dysfunction $=2$	
	Moderate dysfunction $=3$	
	Severe dysfunction $=4$	
	Very severe dysfunction $=5$	
Sensory Classification:	FSSSensory,INT FSS	
	Normal =1	
	Mild dysfunction $=$ <b>2</b>	
	Moderate dysfunction $=3$	
	Severe dysfunction $=4$	
	Very severe dysfunction $=5$	
Communication	FSSCommun,INT	
Classification:	Normal =1	
	Mild dysfunction $=2$	
	Moderate dysfunction $=3$	
	Severe dysfunction $=4$	
	Very severe dysfunction $=5$	
Motor Function Classification:	FSSMotor,INT	
Classification.	Normal = 1	
	Mild dysfunction $=2$	
	Moderate dysfunction $=3$	
	Severe dysfunction $=4$	
	Very severe dysfunction $=5$	
Feeding Classification:	FSSFeeding,INT FSS	
	Normal =1	
	Mild dysfunction $=2$	
	Moderate dysfunction $=3$	
	Severe dysfunction $=4$	
	Very severe dysfunction $=5$	
Respiratory Classification:	FSSResp,INT	
classification.	Normal =1	
	Mild dysfunction $=2$	
	Moderate dysfunction $=3$	
	Severe dysfunction $=4$	
	Very severe dysfunction $=5$	
	, , , , , =	

#### LAPSE PRISM III v1.0

PRISMIII (0/38)							
Title: Pediatric Risk of Mortality Index, V	ersion III						
Instructions: Record the worst physiologic value	ues obtained during the following 6 hour timeframe: 2 ho	ours prior to PICU admiss	ion through 4 hours post PICU admis	sion. If the timeframe spans 2 calendar days, enter	er the first date.		
Date of PRISM III:	PRISMDAY,INT						
Cardiovascular / Neurologic Vital Signs							
Lowest Systolic Blood Pressure (SBP):	PRISMLowSBP,INT (mmHg)	Highest Heart Rate:	PRISMHig	hHeartRate,INT (beats/min)			
Lowest Temperature:	PRISMLowTemp,REAL (°C) HI	ighest Temperature:	PRISMHig	hTemp,REAL (°C)			
How many pupils (select one) were > 3 mm and PR	PRISMPupilReflex,INT	PRISMPupil	ReflexND				
fixed? 0=0 1=1 2=2		Pupillary refle:	xes unable to be assessed due to ede	ma or eye patch =Not done			
Glasgow Coma Scale							
For infants under 2 years of age, use the descri	ined during the following 6 hour timeframe: 2 hour ptions provided in parentheses ().	urs prior to PICU admi	ssion through 4 hours post PICU	admission. Note: The responses for the 3 v.	ariables must be obt	ained from the same assessment.	
4=4 - Eyes ope	PRISMGCSEye,INT ing in response to pain stimulus ing to speech (shout) n spontaneously	Verbal Response:	(select one) GCSVerb 1=1 - No verbal respons 2=2 - Incomprehensible 3=3 - Inappropriate wor 4=4 - Confused (irritable 5=5 - Oriented (coos, ba	ls (cries to pain) ,cries)	Motor Response:	(selectone) GCSMot 1=1 - No response to pain 2=2 - Extension to pain (de 3=3 - Flexion to pain (decor 4=4 - Withdrawal to pain 5=5 - Localized pain 6=6 - Obeys commands (sp	rticate)
At the time of this (select one) GCS assessment, was YN the subject intubated? 1=Yes 0=No	PRISMIntubate,INT	GCS not done =	Not done				
Acid-Base / Blood Gases							
Lowest pH:	PRISMLowpH,REAL (#.##)	Highest pH:	PRISMHig	npH,REAL (#.##)	PRISMpHND Not done = Not	t done	
Lowest PaO2:	PRISMLowPaO2,REAL (mmHg)		PRISMLowPaO2ND,INT ND Not done =Not done				
Highest PCO2:	PRISMHighPCO2,REAL (mmHg)		PRISMHighPCO2ND,INT ND Not done =Not done				
Chemistry Tests							
Lowest Total CO2:	PRISMLowTotalCO2,REAL (mmol/L)	) Highest Total	CO2: PF	ISMHighTotalCO2,REAL (mmol/L)		PRISMTotalCO2ND	
						Not done =Not done	
Highest Serum Glucose:	PRISMHighGlucose,REAL (mg/dL)		PRISMGlucoseND Not done =Not done				
Highest Serum Potassium:	PRISMHighPotassium, REAL (mmol	/L)	PRISMPotassiumND	1			
Highest Creatinine:	PRISMHighCreatinine,REAL (mg/dl	_)	PRISMCreatinineND				
			Not done =Not done				
Highest BUN:	PRISMHighBUN,REAL (mmol/L)		PRISMBUNND				
	- ·		Not done =Not done				
Hematology Tests							
Lowest WBC:	PRISMLowWBC, REAL (10^3/µL)		PRISMWBCND				

Not done =Not done

Lowest Platelets:	PRISMLowPlatelet,REAL (10^3/µL)	PRISMPlateletND Not done =Not done	
Highest PT:	PRISMHighPT,REAL (seconds)	PRISMPTND Not done =Not done	
Highest PTT:	PRISMHighPTT,REAL (seconds)	PRISMPTTND Not done =Not done	

#### LAPSE CNS Parameter Data v1.0

CNS (0/11)		
Title: CNS Parameter Data		
Instructions: Indicate each of the for Study day definitions Study day 0 (zero): PICU admissi All other study days: 0000 to 23 Discharged prior to day 28: 000	59	
Date:	CNSDAY, INT	
Indicate which of the following occur Anisocoria or absence (selec of pupillary response: YN	rred on this study day: ct one) Anisocoria,INT	
1=Ye 0=Ne	es O	
Pathologic breathing (select pattern: YN 1=Ye 0=Ne	es o	
Stereotypic posturing (select or flaccid posture: YN 1=Ye 0=Ne	es	
Seizure activity and / (select or abnormal EEG: YN 1=Ye 0=Ne		
New anoxic-ischemic (select injury on CT/MRI YN imaging: 1=Ye 0=Ne	es	
Treatment for (select increased intracranial YN pressure: 1=Ye 0=Net	es o	

Neurologic injury (select one) suspected by care YN provider: 1=Yes 0=No	SuspectedInjury,INT
Autonomic storming: (select one) YN 1=Yes 0=No	AutonomicStorming, INT
Cardiopulmonary (select one) arrest or chest YN compressions: 1=Yes 0=No	CPR,INT

#### LAPSE Fluid Parameters v1.0

Fluid (0/8)		
Title: Fluid Parameters		
Instructions: Obtain the 24 hour TOTAL volu	me for each fluid parameter below. For study days that are less	than 24 hours (Day 0, Day of discharge), still record the 24 hour total from 0000-2359.
Study day definitions Study day 0 (zero): PICU admission until 23 All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PICU d		
Date:	FLUIDDAY INT	
l's & O's		
Total Fluid Intake:	TotalIntake,REAL (mL)	
Total Fluid Output:	TotalOutput, REAL (mL) Total Urinary O	utput: UrinaryOutput,REAL (mL)
Transfusions		
If a particular transfusion did not occur, record	0 (zero) for the total volume.	
Total PRBC Tranfusion:	PRBCTransfusion, REAL (mL)	
Total platelet transfusion:	PlateletTransfusion,REAL (mL)	
Total FFP transfusion:	PlasmaTransfusion, REAL (mL)	

#### LAPSE Laboratory Values v1.0

	SingleV(0/20) AllValu(0/26) SingleV(0/20)	ect to Jump									
	Title: Daily Labs: ALL VALUES AVAILABLE										
	Instructions: Record all values for each lab indicated below t	for this study day.									
	Study day definitions Study day 0 (zero): PICU admission until 2359 All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PICU discharge Table name: Labs_Common										
	Time (HHMM)	Platelet Count (10^3/µL)	Fibrinogen (mg/dL)	Fibrin Degradation Products Titer (µg/mL)	D-dimer	D-dimer Un	it	PT (seconds)	Arterial Lactate Concentration	Arterial L Concentr Unit	ration
LABDAY, INT	CommonLabsTime,ST	PlateletCount,REAL	Fibrinogen,REAL	FibrinDegrad,REAL	Ddimer, REAL	(select one) Do Dimer 1=ng/mL D-DU 2=ng/mL FEU 3=micrograms/mL FE 4=mg/L FEU	dimerUnit,INT EU	PT,REAL	ArtLactate,REA	(select one) ArtLi ArtLac 1=mg/dL 2=mmol/L	actateUnit,INT
	Add										
	Table name: Labs_Rare										
	Time (HHMM)		Amylase (IU/L)	Lipase (IU/L)	C-Reactiv (CR (mg/	(P)		Ferritin (ng/mL)	Fre	ee Hemoglobin (mg/dL)	
LABDAY, INT	RareLabsTime,ST	Am	vlase,REAL	Lipase, REAL	CRP,	REAL		Ferritin,REAL	Fre	eHgb,REAL	X
	Add										
	scozs Table name: Labs_SCD	Time		sCD25							
		(HHMM)		(pg/mL)					Upload Results		
LABDAY, INT	SCDTime,ST		SCDT	wentyFive,REAL				Valu	e not provided		x
	Add										
	Bone Marrow Biopsy Results Table name: Labs_Bone										
		Time (HHMM)		Bor	e Marrow Results				Upload Results		
LABDAY, INT	BoneMarrowTime,ST			(select one) BoneMarrow,INT PosNeg 1=Positive 0=Negative				Value	not provided		X
	Add										
	Genotyping for perforin mutations Table name: Labs_Geno			1							
		Time (HHMM)		Peri	orin Mutation ienotyping				Upload Results		
LABDAY, INT	GenotypingTime,ST			(selectone) Genotyping,INT Present 1=Present 0=Not present				Value i	not provided		x
	Add Natural Killer Cells Activity Table name: Labs_NkCells										
	Table name, Labs_NKCells	Time (HHMM)						Upload Results			
LABDAY, INT	NKActivityTime,ST	(1000)				Value not	t provided				X
	Add				1						
	<u> </u>										

#### LAPSE Laboratory Values v1.0

SingleV(0/20) AllValu(0/26)	Select to Jump	
Title: Daily Labs: SINGLE VALUE ONLY	,	
Instructions: Record the lowest / highest va	alue for each lab indicated below for this study day.	
Study day definitions Study day 0 (zero): PICU admission until All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PIC		
Date:	LABDAY INT	
LOWEST VALUES		
Absolute lymphocyte	LowLymphocyte,REAL (10^3/µL)	LymphocyteND
count (ALC):	Loweymphocyte, REAL (****)	
		Not done =Not done
Absolute neutrophil count (ANC):	LowNeutrophil,REAL (10^3/µL)	NeutrophilND
		Not done =Not done
Hemoglobin:	LowHemoglobin,REAL (g/dL)	HemoglobinND
		Not done =Not done
HIGHEST VALUES		
INR:	HighINR,REAL	INRND
	-	Not done =Not done
BUN:	HighBUN,REAL (mg/dL)	BUNND
		Not done =Not done
Total bilirubin:	HighBilirubin,REAL (mg/dL)	BilirubinND
	<u> </u>	Not done =Not done
ALT:	HighALT, REAL (IU/L)	ALTND
		Not done =Not done

LDH:	HighLDH,REAL (IU/L)	LDHND
		Not done =Not done
Triglycerides:	HighTriglycerides, REAL (mg/dL)	TriglyceridesND
		Not done =Not done

#### LAPSE PELOD 2 v1.0

PELOD (0/21)			
Title: Pediatric Logistic Organ Dysfunct	tion Score II		
Instructions: Record the worst physiologic v	alues obtained on this study day. Refer to the MOO for detailed	d instructions on completing this assessment.	
Study day definitions Study day 0 (zero): PICU admission until All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PICU			
Date:	PELODDAY, INT		
Glasgow Coma Scale			
Record the worst (lowest) GCS score co		s variables must be obtained from the same assessment.	
For infants under 2 years of age, use the des			
Eye Response: (select one) GCSEye 1=1 - No eye 2=2 - Eye ope 3=3 - Eye ope 4=4 - Eyes op	PELODGCSEye,INT opening ming in response to pain stimulus ning to speech (shout) en spontaneously	Verbal Response:     (select one)     PELODGCSVerbal,INT       GCSVerb     1=1 - No verbal response     2=2 - Incomprehensible sounds (moans to pain)       3=3 - Inappropriate words (cries to pain)     3=4 - Confused (irritable,cries)       5=5 - Oriented (coos, babbles)	Motor Response:         eelectone)         PELODGCSMotor,INT           GCSMot         1=1 - No response to pain         1=2           2=2 - Extension to pain (decerebrate)         3=3 - Flexion to pain (decorticate)         4=4 + Withdrawal to pain           5=5 - Localized pain         5=5 - Obeys commands (spontaneous)         5=6
At the time of this (select one) GCS assessment, was YN the subject intubated? 1=Yes 0=No	PELODIntubate, INT	PELODGCSND,INT GCSND GCS not done =Not done	
Cardiovascular / Neurologic Vital Signs			
Lowest Mean Arterial Pressure (MAP):	PELODMAP,REAL (mmHg)		
How many pupils (select one) were > 3 mm and PR fixed? 0=0 1=1 2=2	PELODPupilReflex, INT	PELODPupilReflexND Pupillary reflexes unable to be assessed due to edema or eye patch =Not done	
Renal			
Highest Renal Creatinine:	PELODHighCreatinine,REAL (mg/dL)	PELODHighCreatinineND Not done =Not done	
Respiratory			
	e time. Record the values that calculate the lowest PaO2/FiO2	ratio.	
PaO2:	PELODPaO2, REAL (mmHg)	PELODPaO2ND	
		Not done =Not done	

FiO2:	PELODFiO2,REAL (#.##) Must be a decimal	PELODFiO2ND Not done = Not done			
Highest PaCO2:	PELODHighPaCO2,REAL (mmHg)	PELODHighPaCO2ND Not done =Not done			
Has the subject required <i>invasive</i> mechanica	as the subject required <i>invasive</i> mechanical ventilation at any time on this study day?				
(select one) YN 1=Yes 0=No	PELODMechVent,INT				
Hematologic					
Lowest WBC:	PELODLowWBC,REAL (10^3/µL)	PELODLowWBCND Not done =Not done			

# LAPSE PICU Interventions / Clinical Findings v1.0

PICUInt(0/20)					
Title: PICU Interventions / Clinical Find	lings				
Instructions: Indicate the PICU interventions and clinical findings that occurred at any time on this study day. Findings need NOT occur at the same time. Study day definitions Study day 0 (zero): PICU admission until 2359 All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PICU discharge					
Date:	PICUINTERVENDAY,INT	(select one)			
	and and fine 2				
On this study day, did any of the following or Infectious nidus (select one) removed: YNNAU 1=Yes 0=No 96=Not ap 92=Unkno	InfectiousNidus,INT				
Inflammation source (select one) effectively removed: YNNAU 1=Yes 0=No 96=Not ap 92=Unkno	InflammSource,INT plicable				
Mechanical ventilation (select one) (invasive or non- invasive): YN 1=Yes 0=No	MechVent,INT				
High frequency (select one) ventilation (oscillator YN or jet): 1=Yes 0=No	HFV,INT				
Extracorporeal (select one) support (ECMO or VAD): 1=Yes 0=No	ECMO,INT				
Renal replacement (select one) therapy	RRT,INT				

(hemofiltration or YN dialysis): 0=No	
Cardiopulmonary (select one) arrest or chest YN compressions: 1=Yes 0=No	CPR,INT
Treatment for (select one) increased intracranial YN pressure: 1=Yes 0=No	ICP,INT
Immune suppressant (select one) tapered by 50%: YN 1=Yes 0=No	ImmuneSuppress,INT
Plasma exchange (select one) therapy: YN 1=Yes 0=No	PlasmaExchange,INT
Indwelling arterial (select one) catheter: YN 1=Yes 0=No	ArterialCatheter,INT
Indwelling urinary (select one) catheter: YN 1=Yes 0=No	UrinaryCatheter,INT
Indwelling central (select one) venous catheter: YN 1=Yes 0=No	VenousCatheter,INT
Endotracheal tube in (select one) place: YN 1=Yes 0=No	ETT,INT
Tracheostomy in (select one) place: YN 1=Yes 0=No	Tracheostomy,INT
Splenomegaly: (select one) YN 1=Yes 0=No	Splenomegaly,INT
Neuromuscular (select one) blocker: YN 1=Yes 0=No	NMB,INT
Parenteral nutrition: (select one) YN 1=Yes 0=No	TPN,INT

# LAPSE Respiratory Parameter Data v2

The Record be anteneous of constructions records and an end of the set of the	<b>8AM</b> (0/17) 8PM	(0/15)	Select to Jump				
Subjective definitions       S	Title: Respiratory Param	neter Data at a	3 AM				
Skub v dy 0 c cevol: TCU J definition util 2337 Behanged prior to dy 28 0000 PCU uschinge Dute: RESPIRATORYDAY,INT Visition and y definition of the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomoters below were callected? With the subject receiving investor or monitowate mechanical vestilation at the time the pomotereceiving investor or monitowate mechanical vestilation at the ti	Instructions: Record the sir	nstructions: Record the simultaneously occurring respiratory parameter values obtained closest to 8AM on this study day.					
Wee the subject receiving invasive or non-invasive mechanical ventilation at the time the parameters below were collected?           Wee the subject receiving invasive or non-invasive mechanical ventilation at the time the parameters below were collected?           Vin Ventilanza Ventila	Study day 0 (zero): PICL All other study days: 000	00 to 2359					
Wee the subject recoving invoke or non-voketed versibilition at the inner the parameters below were collected?         View divelopment in the subject recoving invoket or non-voket model were collected?         View divelopment in the subject recoving invoket or non-voket model were collected?         View divelopment in the subject recoving invoket or non-voket model were collected?         View divelopment in the subject recoving invoket model were collected?         Diversitier were the subject recovering invoket model were collected?         View diversitier were collected?         View diversit were collected?	Date	:	RESPIRATORYDA	AY.INT			
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM,ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM,ST         Invasive ventilator mode       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeAM, INT         VentInvasiveModeOtherAM,ST       VentNonInvModeOtherAM,ST         VentNonInvModeAM, INT       Other vent mode:         VentNonInvModeOtherAM,ST       VentNonInvModeOtherAM,ST         VentNonInvModeOtherAM,ST       Pulse Oximetry         Pulse Oximetry       RespSpO2AM,INT (%)         FiO2:       FiO2AM,REAL (#.##) (must be a decimal)							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM,ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM,ST         Invasive ventilator mode       VentInvasiveAdeAM, INT         Other vent mode:       VentInvasiveAdeAM, INT         VentInvasiveModeOtherAM, INT       Other vent mode:         Non-invasive (select one)       VentInvandeAM, INT         Other vent mode:       VentNonInvModeAM, INT         VentInvasiveAdeAM, INT       Other vent mode:         VentNonInvModeOtherAM, ST       VentNonInvModeOtherAM, ST         Pulse Oximetry       RespSpO2AM, INT (%)         FiO2       FiO2AM, REAL (#.##) (must be a decimal)							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeAM, INT         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentNonInvModeOtherAM, INT       Other vent mode:         VentNonInvModeOtherAM, ST       Pulse Oximetry         Pulse Oximetry       RespSpO2AM, INT (%)         FIO2:       FIO2AM, REAL (#.##) (must be a decimal)							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeAM, INT         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentNonInvModeOtherAM, INT       Other vent mode:         VentNonInvModeOtherAM, ST       Pulse Oximetry         Pulse Oximetry       RespSpO2AM, INT (%)         FIO2:       FIO2AM, REAL (#.##) (must be a decimal)							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeAM, INT         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentNonInvModeOtherAM, INT       Other vent mode:         VentNonInvModeOtherAM, ST       Pulse Oximetry         Pulse Oximetry       RespSpO2AM, INT (%)         FIO2:       FIO2AM, REAL (#.##) (must be a decimal)							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeAM, INT         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentInvasive (select one)       VentNonInvModeAM, INT         Other vent mode:       VentNonInvModeOtherAM, ST         VentNonInvModeOtherAM, INT       Other vent mode:         VentNonInvModeOtherAM, ST       Pulse Oximetry         Pulse Oximetry       RespSpO2AM, INT (%)         FIO2:       FIO2AM, REAL (#.##) (must be a decimal)							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM,ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM,ST         Invasive ventilator mode       VentInvasiveAdeAM, INT         Other vent mode:       VentInvasiveAdeAM, INT         VentInvasiveModeOtherAM, INT       Other vent mode:         Non-invasive (select one)       VentInvandeAM, INT         Other vent mode:       VentNonInvModeAM, INT         VentInvasiveAdeAM, INT       Other vent mode:         VentNonInvModeOtherAM, ST       VentNonInvModeOtherAM, ST         Pulse Oximetry       RespSpO2AM, INT (%)         FiO2       FiO2AM, REAL (#.##) (must be a decimal)							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
(select one)       MechanicalVentAM, INT         1=Yes       VentInvasiveModeAM, INT         Invasive ventilator       (select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator       Select one)         Invasive ventilator       VentInvasiveModeAM, INT         Other vent mode:       VentInvasiveModeOtherAM, ST         Invasive ventilator mode       VentInvasiveApplication         Non-invasive       VentInvasiveApplication         VentInvasive ventilator mode       VentInvasiveApplication         VentInvasive (select one)       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInvasiveApplication         VentInvasiveApplication       VentInva							
YN       = Yes         Invasive ventilator       (select one)         VentilonInvModeAM,INT       Other vent mode:         VentilonInvModeAM,INT       Other vent mode:         Ventilotor mode       (nask)         (nask)       (select one)         Ventilotor mode       (sep2):         Select one)       (sep2):         FI02       FI02AM,REAL (#.##) (must be a decimal)	Was the subject receiving in	vasive or non-ir			eters below were	collected?	
1=Yes 0=N0       Invasive ventilator mode:       (select one) 1=Pressure control 2=PRVC 3=APRV 4=HF3V 5=HFOV 6=Volume control 7=Pressure support and CPAP 90=Other       Other vent mode:       VentInvasiveModeOtherAM,ST         Non-invasive (select one) ventilator mode (mask):       VentInvanive 2=PRVC 3=APRV 4=HF3V       Other vent mode:       VentInvasiveModeOtherAM,ST         Non-invasive (select one) ventilator mode (mask):       VentInvolume control 2=PRVC 3=APRV 4=HF3V       Other vent mode:       VentInvasiveModeOtherAM,ST         Non-invasive (select one) ventilator mode (mask):       VentInvolume control 2=PRVC 3=APRV 4=HF3V       Other vent mode:       VentInvasive select one)         Pulse Oximetry (Sp02):       RespSp02AM,INT (%)       Other vent mode:       VentInvolume control 2=PRVC 4=CPAP 2=PRVC 4=HF3V         FI02:       FI02AM,REAL (#,##) (must be a decimal)       FI02AM,REAL (#,##) (must be a decimal)       FI02AM,REAL (#,##) (must be a decimal)			MechanicalVentAM,IN	Γ			
Invasive ventilator       (select one)       VentInvasiveModeAM,INT       Other vent mode:       VentInvasiveModeOtherAM,ST         Invasive ventilator       InvMode       Investige       SepRV       VentInvasiveModeOtherAM,ST         2=PRVC       3=APRV       4=HFDV       SepRV       VentInvasiveModeOtherAM,ST         90=Other       VentInvasive       VentInvasive       VentInvasive       VentInvasiveModeOtherAM,ST         Non-invasive       (select one)       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         ventilator mode       NonMode       1=CPAP       2=BIPAP       Other vent mode:       VentNonInvModeOtherAM,ST         Pulse Oximetry       RespSpO2AM,INT (%)       EFO2       FIO2AM,REAL (#.##) (must be a decimal)       VentInvasive in the investige		1=Yes					
mode:       InvMode       1=Pressure control       2=PRVC         3=APRV       4=HFJV       5=HFOV       6=Volume control         5=Volume control       7=Pressure support and CPAP       90=Other         90=Other       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         ventilator mode       Non-invasive       (select one)       VentNonInvModeAM,INT       Other vent mode:         ventilator mode       Non-Mode       (select one)       VentNonInvModeAM,INT       Other vent mode:         Pulse Oximetry       RespSpO2AM,INT (%)       FiO2:       FiO2AM,REAL (#.##) (must be a decimal)	Invasive ventilato		VontInvosi	voModo M	TNIT	Other vent mode:	VantInuaciyaMadaOtharAM CT
2=PRVC 3=APRV 4=HFJV 5=HFOV 6=Volume control 7=Pressure support and CPAP 90=Other       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         Non-invasive ventilator mode (mask): 1=CPAP 2=BiPAP 90=Other       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         Non-invasive (mask): 1=CPAP 2=BiPAP 90=Other       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         Pulse Oximetry (SpO2):       RespSpO2AM,INT (%)       FiO2AM,REAL (#.##) (must be a decimal)		<sup>1</sup> InvMode		VelvioueAlvi	,1111	other venemode.	VentitivasivemodeOtherAm, ST
3= APRV 4= HFDV 5= HFDV 6= Volume control 7= Pressure support and CPAP 90= Other       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         Non-invasive ventilator mode (mask): 2= BiPAP 90= Other       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         Pulse Oximetry (sp02):       RespSp02AM,INT (%)       EspSp02AM,INT (%)       EspSp02AM,INT (%)         Fi02:       Fi02AM,REAL (#.##) (must be a decimal)       EspSp02AM,INT (%)		2=PRVC	re control				
S=HFOV 6=Volume control 7=Pressure support and CPAP 90=Other         Non-invasive ventilator mode (mask):       (select one) NonMode 1=CPAP 2=BiPAP 90=Other       VentNonInvModeOtherAM,ST         Pulse Oximetry (SpO2):       RespSpO2AM,INT (%)       VentNonInvModeOtherAM,ST         FiO2:       FiO2AM,REAL (#.##) (must be a decimal)		3=APRV 4=HFJV					
7=Pressure support and CPAP         90=Other         Non-invasive (select one)       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         NonMode (mask):       1=CPAP 2=BiPAP 90=Other       Other vent mode:       VentNonInvModeOtherAM,ST         Pulse Oximetry (SpO2):       RespSpO2AM,INT (%)       VentNonInvMode 4 decimal)         FiO2:       FiO2AM,REAL (#.##) (must be a decimal)		5=HFOV 6=Volume	e control				
Non-invasive ventilator mode (mask):       (select one) NonMode 1=CPAP 2=BiPAP 90=Other       VentNonInvModeAM,INT       Other vent mode:       VentNonInvModeOtherAM,ST         Pulse Oximetry (SpO2):       RespSpO2AM,INT (%)            FiO2:       FiO2AM,REAL (#.##) (must be a decimal)		7=Pressu 90=Other	re support and CPAP				
Ventilator mode (mask):       NonMode 1=CPAP 2=BiPAP 90=Other         Pulse Oximetry (SpO2):       RespSpO2AM,INT (%)         FiO2:       FiO2AM,REAL (#.##) (must be a decimal)	Non-invasive	2		NT	Other vent mode		VontNonInvModeOthorAM ST
Pulse Oximetry (SpO2):       RespSpO2AM,INT (%)         FiO2:       FiO2AM,REAL (#.##) (must be a decimal)	ventilator mode (mask)	<sup>e</sup> NonMode	VentroninvinodeAn,i				Ventronitin ModeounerAm, 51
Pulse Oximetry (SpO2):     RespSpO2AM,INT (%)       FiO2:     FiO2AM,REAL (#.##) (must be a decimal)	(	Z=DIPAP					
FiO2: FiO2AM,REAL (#.##) (must be a decimal)		90=Other					
			RespSpO2AM,IN	<b>T</b> (%)			
PaO2: PaO2AM,REAL (mmHg)	FiO2	:	FiO2AM,REAL (#-	##) (must be a	a decimal)		
	PaO2	:	PaO2AM,REAL (n	nmHg)			

PaCO2:	PaCO2AM,REAL (mmHg)	
ETCO2:	ETCO2AM,REAL (mmHg)	
PEEP:	PEEPAM,REAL (cmH20)	
PIP:	PIPAM,REAL (cmH20)	
MAP:	MAPAM,REAL (cmH20)	
Exhaled tidal volume:	VTExhaledAM,REAL (mL)	
Was the subject receiving nitric oxide at the time the above parameters were collected?	es o	

# LAPSE Respiratory Parameter Data v2

<b>8AM (0/17)</b>	M (0/15)	Select to Jump			
Title: Respiratory Parame	eter Data at 8	PM			
Instructions: Record the sim	ultaneously occu	urring respiratory parameter values obtained	closest to 8PM on	this study day.	
Study day definitions Study day 0 (zero): PICU All other study days: 0000 Discharged prior to day 2	0 to 2359				
Was the subject receiving inv	asive or non-inv	asive mechanical ventilation at the time the p	arameters below we	ere collected?	
	(select one) YN 1=Yes 0=No	MechanicalVentPM,INT			
	InvMode 1=Pressure 2=PRVC 3=APRV 4=HFJV 5=HFOV 6=Volume		∋PM,INT	Other vent mode:	VentInvasiveModeOtherPM,ST
	(select one) NonMode 1=CPAP 2=BiPAP 90=Other	VentNonInvModePM,INT	Other vent mo	ode:	VentNonInvModeOtherPM,ST
Pulse Oximetry (SpO2):		RespSpO2PM,INT (%)			
FiO2:		FiO2PM,REAL (#.##) (mus	t be a decimal)		
PaO2:		PaO2PM,REAL (mmHg)			
PaCO2:		PaCO2PM,REAL (mmHg)			
ETCO2:		ETCO2PM,REAL (mmHg)			
PEEP:		PEEPPM,REAL (cmH20)			
PIP:		PIPPM,REAL (cmH20)			
Mean Airway Pressure (MAP):		MAPPM,REAL (cmH20)			
Exhaled tidal volume:		VTExhaledPM,REAL (mL)	)		
Was the subject receiving nitric oxide at the time the above parameters were collected?	(select one) YN 1=Yes 0=No	NOPM,INT			

#### LAPSE Vasoactive Inotropic Score v1.0

8AM (0/12) 8PM	(0/10)	Select to Jump	
itle: Vasoactive Inotro			
structions: Record all IV mount given.	continuously infu	sed vasoactive medications being administered to the subject at $exa$	actly 8 AM. If a medication listed below is not being administered, record 0 for the
tudy day definitions tudy day 0 (zero): PICL II other study days: 00 ischarged prior to day	00 to 2359		
Date	2:	VISDAY,INT	(select one)
the subject receiving vaso	oactive drips at ex		
	(select one) YN 1=Yes 0=No	VasoDripsAM,INT	
Dopamine	2:	VISDopamineAM,REAL (µg/kg/min)	
Dobutamine	2:	VISDobutamineAM,REAL (µg/kg/min)	
Nitroprusside	2:	VISNitroprussideAM,REAL (µg/kg/min)	
Milrinone	2:	VISMilrinoneAM,REAL (µg/kg/min)	
Epinephrine	:	VISEpinephrineAM,REAL (µg/kg/min)	
Norepinephrine	2:	VISNorepinephrineAM,REAL (µg/kg/min)	
Phenylephrine	2:	VISPhenylephrineAM,REAL (µg/kg/min)	
Vasopressin	1:	VISVasopressinAM,REAL	Unit: (select one) VISVasopressinUnitAM,INT VasoUnit 1=munits/kg/hr 2=units/kg/hr 3=units/hr 4=munits/kg/min

# LAPSE Vasoactive Inotropic Score v1.0

8AM (0/12) 8PM (0/10) Select	t to Jump	
Title: Vasoactive Inotropic Score at 8 PM		
Instructions: Record all IV continuously infused vasa amount given. Study day definitions Study day 0 (zero): PICU admission until 2359 All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PICU discha		ctly 8 PM. If a medication listed below is not being administered, record 0 for the
Is the subject receiving vasoactive drips at exactly 8	PM?	
(select one) Vas YN 1=Yes 0=No	soDripsPM,INT	
Dopamine:	VISDopaminePM,REAL (µg/kg/min)	
Dobutamine:	VISDobutaminePM,REAL (µg/kg/min)	
Nitroprusside:	VISNitroprussidePM,REAL (µg/kg/min)	
Milrinone:	VISMilrinonePM,REAL (µg/kg/min)	
Epinephrine:	VISEpinephrinePM,REAL (µg/kg/min)	
Norepinephrine:	VISNorepinephrinePM,REAL (µg/kg/min)	
Phenylephrine:	VISPhenylephrinePM,REAL (µg/kg/min)	
Vasopressin:	VISVasopressinPM,REAL	Unit: (select one) VISVasopressinUnitPM,INT VasoUnit 1=munits/kg/hr 2=units/kg/hr 3=units/hr 4=munits/kg/min 5=units/kg/min

#### LAPSE Vital Measurements v2

<b>8AM (0/8)</b> 8PM (0/6)	lect to Jump				
Title: Vital Sign Data at 8 AM					
Instructions: Record the simultaneously occurr	ing vital measurements obtained closest to 8	AM on this study day.			
Study day definitions Study day 0 (zero): PICU admission until 2359 All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PICU discharge					
Date:	VitalsDay,INT		(select one)		
	vitaisbay, ivi		(Select offe)		
Systolic BP:	SBPAM, INT (mmHg)	Diastolic BP:	DBPAM,INT (mmHg)		
Mean Arterial BP:	MeanBPAM,INT (mmHg)				
Central Venous Pressure:	CVPAM,INT (mmHg)				
Central Venous	ScvO2AM,INT (%)	ScvO2AM	ND		
Oxygen Saturation	·	Not such			
(ScvO2):		NOT AVAILAD	<sup>ble</sup> =Not done		

#### LAPSE Vital Measurements v2

<b>8AM</b> (0/8) <b>8PM</b> (0/6) Select	to Jump		
Title: Vital Sign Data Data at 8 PM			
Instructions: Record the simultaneously occurring	vital measurements obtained closest t	o 8PM on this study day.	
Study day definitions Study day 0 (zero): PICU admission until 2359 All other study days: 0000 to 2359 Discharged prior to day 28: 0000 to PICU disc	harge		
Systolic BP:	SBPPM,INT (mmHg)	Diastolic BP:	DBPPM,INT (mmHg)
Mean Arterial BP:	MeanBPPM,INT (mmHg)		
Central Venous Pressure:	CVPPM,INT (mmHg)		
Central Venous Oxygen Saturation (ScvO2):	ScvO2PM,INT (%)	ScvO2PMND Not available	) =Not done

## LAPSE Biomarker Sample Collection v1

Biomark(0/8)				
Title: Biomarker Collecti	on			
Was a LAPSE biomarker sam	ple collected with	in 24 hours of PICU admission?		
	(select one) YN 1=Yes 0=No	Biomarker24Hour,INT *		
Date Collected:		BIOMARKER24DAY, INT	Time Collected:	Biomarker24Time,ST (HHMM)
Was a LAPSE biomarker sam	Was a LAPSE biomarker sample collected within 48 to 72 hours of PICU admission?			
	(select one) YN 1=Yes 0=No	Biomarker48Hour,INT		
Date Collected:		BIOMARKER48DAY, INT	Time Collected:	Biomarker48Time,ST (HHMM)
Shipping Information				
Date Shipped:	:	SHIPPEDDAY INT	Tracking Number:	Value not provided

# LAPSE Withdrawal from Study Participation v1

e: Withdrawal from Stu	dy Participation		
Date permission withdrawn:	SUBJECTWITHDRAWNDAY, INT	Time permission withdrawn:	SubjectWithdrawnTime,ST * (HHMM
Reason for subject <b>R</b> withdrawal:	easonWithdrawn *	Specify:	OtherReasonWithdrawn,ST
(select all that apply)	Decision made to limit aggressive intensive care Subject		
	became a ward of the state		
	No longer able to participate in long term follow-up Other (specify)		

Variable Name	Label / Description	Values / Format
ReasonWithdrawn1	Decision made to limit aggressive intensive care	1 = Yes, 0 = No
ReasonWithdrawn2	Subject became a ward of the state	1 = Yes, 0 = No
ReasonWithdrawn3	No longer able to participate in long term follow-up	1 = Yes, 0 = No
ReasonWithdrawn90	Other (specify)	1 = Yes, 0 = No

# Table Name: Devices

Variable Name Timepoint Label / Description Time point

Device DeviceSourceType Device/Device category Source of device reporting Values / Format 1 = Baseline 2 = Day 7 3 = Day 28 4 = 3 months 5 = 6 months 6 = 12 months CHAR 1 = Caregiver 2 = RC (select) 3 = RC (select other) 4 = RC (Chronic)

## Table Name: Medications

Variable Name Medication SourceType

MEDSTARTDAY MEDSTOPDAY MedContinue STEROIDDAY SteroidTotalDose SteroidUnit Medication start date Medication stop date Non-Steroid medication continuing on Day 28 or PICU discharge Steroid date Total steroid dose Steroid dose unit

Label / Description

Source of medication record

Medication

CodedMedication NoRXCodedMedName MedType Code MedTimepoint Medication (RxNorm) RxNorm medication code name not found Medication type (RxNorm) Medication code (RxNorm) Study time point medication administered

Status REDCapStatus REDCapStatusCode REDCapCodedMedName REDCapMedCode Coding status Coding status (PI coding) Coding status code (PI coding) Coded medication name (PI coding) Medication code (PI coding) Values / Format CHAR 1 = Caregiver (DatStat)2 = RC (DatStat)3 =Antimicrobial log (OC) 4 = Immune log (OC)5 =Steroids log (OC)" INT INT 1 = Yes, 0 = NoINT NUM 1 = mcg2 = mg3 = g5 = mcg/kg/min6 = mg/kg/min7 = meq/kg/min8 = mI9 = ml/hr10 = puffs11 = units12 = units/hr14 = meq90 = Other (specify)93 = Unable to Determine 94 = Not documented CHAR 1 = Yes, 0 = NoCHAR CHAR 1 = Baseline2 = Day 7 3 = Day 284 = 3 months 5 = 6 months 6 = 12 months CHAR CHAR NUM CHAR NUM

### Table Name: MicroAbstractions

Variable Name ItemGroupRepeatKey AlternateItemGroupRepeatKey MICRODAY MICROBIOLOGYDAY MicroDateType	Label / Description Item group repeat key OC review site item group repeat key OC microbiology date Microbiology abstraction date Microbiology abstraction date type	Values / Format NUM NUM INT 1 = Collection Date 2 = Culture/Test Start Date 3 = Result Date 92 = Unknown
PMN	Polymorphonuclear leukocytes (PMN)	1 = Few 2 = Moderate 3 = Many 97 = Present - unknown amount"
SampleSite	Sample site	<ul> <li>1 = Abscess</li> <li>2 = Blood</li> <li>3 = Bronchial brush</li> <li>4 = Bronchoalveolar lavage</li> <li>5 = Nasopharyngeal</li> <li>6 = Pleural fluid</li> <li>7 = Peritoneal fluid</li> <li>8 = Skin</li> <li>9 = Spinal fluid</li> <li>10 = Sputum</li> <li>11 = Stool / Rectal</li> <li>12 = Surgical site</li> <li>13 = Urine</li> <li>14 = Vascular catheter</li> <li>15 = Wound (non-surgical)</li> <li>90 = Other</li> </ul>
TestType	Test type	1 = Culture 2 = PCR 90 = Other
TestResult	Test result	0 = Negative 1 = Positive 2 = Contaminant
UploadCollect	Upload collection	1 = Log upload 2 = Eligibility upload

# Table Name: MicroOrganisms

Variable Name
Organism
GramPositive
GramNegative
GramVariable
Viral
Fungal
Parasitic
OtherPositive
BacterialPositive
ViralPositive
UnknownOrganism
UploadCollect
InfectionType

#### Label / Description Organism name Gram positive Gram negative Gram variable Viral Fungal Parasitic Other positive Bacterial positive PCR positive Unclassified organism Upload collection Type of infection

#### Values / Format

CHAR
1 = Yes, 0 = No
1 = Log upload
2 = Eligibility upload
0 = Multple infection types
1 = Gram positive
2 = Gram negative

3 = Gram variable

- 4 = Viral
- 5 = Fungal
- 6 = Parasitic
- 7 = Other positive

# Table Name: EnrolledSubjects

Variable Name	Label / Description
PMCA	Medical complexity algorithm category
	(3 years prior LAPSE admission)

TimePointDeath Vital status at study time points

Values / Format

- 1 = No chronic comorbid conditions
- 2 = Chronic comorbid conditions (non-complex)
- 3 = Chronic comorbid conditions (complex)
- .P = Missing PHIS
- .K = Missing Diagnoses
- 1 = Death Day 7
- 2 = Death Day 28
- 3 = Death Month 3
- 4 = Death Month 6
- 5 = Death Month 12
- 6 = Alive

LAPSE OpenClinica Subject ID:

Contains: LAPSE_STUDY_NO	
Question: LAPSE_STUDY_NO Required	
APSE OpenClinica Subject ID	Value not provided
Question: PICU_ADMIT_DATE_ENTERED	
	it date and time (must be within 48 hours of Date the survey is being tal /YYYY HH:MM AM/PM Value not provided
ito Page Break	
	Hours_since_admit = calculated difference between
Question: PICU_DATE_OVERRIDE Show if: (HOURS_SINCE_ADMIT >= 500)	entered PICU admit date and date the survey is taken
	e enter it here:Remember, this is only to be used by special arrangement where a paper survey that was administered during the correct window is Value not provided
	dmit_Date_Entered  displayed Value not provided
ours since PICU admit: [Hours]	Since_Admit] displayed Value not provided
collection: DATE_WARN_GROUP contains: Show if: (HOURS_SINCE_ADMIT >	48) or (AGEINMONTHS < 0)
WARNING	
	urs since the PICU admit date/time.
It has been more than 48 hours if the entered date is in error, please	<b>urs since the PICU admit date/time.</b> e use the PREVIOUS button to go back and enter the correct PICU admit
It has been more than 48 hou If the entered date is in error, please date/time.	-
It has been more than 48 hou If the entered date is in error, please date/time. age Break	-
It has been more than 48 hou If the entered date is in error, please date/time.	e use the PREVIOUS button to go back and enter the correct PICU admit
It has been more than 48 hours of the entered date is in error, please date/time.	e use the PREVIOUS button to go back and enter the correct PICU admit
It has been more than 48 hou         if the entered date is in error, please         date/time.         age Break         Collection: DATE_STOP_GROUP Contains: Show if: (DATE_STOP = 1)         Va         WARNING	e use the PREVIOUS button to go back and enter the correct PICU admit
It has been more than 48 hou         if the entered date is in error, please         date/time.         age Break         Collection: DATE_STOP_GROUP Contains: Show if: (DATE_STOP = 1)         WARNING         It has been 500 or more ho	e use the PREVIOUS button to go back and enter the correct PICU admit
It has been more than 48 hou If the entered date is in error, please date/time. age Break Collection: DATE_STOP_GROUP Contains: Show if: (DATE_STOP = 1) Va WARNING It has been 500 or more ho We assume this date is in error. R Jump-To: JMP1-BACK	e use the PREVIOUS button to go back and enter the correct PICU admit ilue not provided burs (20 days) since the PICU admit date/time. tegistration cannot continue without a valid date. If Hours_Since_Admit >= 500 and no valid override code is
It has been more than 48 hou If the entered date is in error, please date/time. age Break Collection: DATE_STOP_GROUP Contains: Show if: (DATE_STOP = 1) Va WARNING It has been 500 or more ho We assume this date is in error. R	e use the PREVIOUS button to go back and enter the correct PICU admit alue not provided burs (20 days) since the PICU admit date/time. tegistration cannot continue without a valid date. If Hours_Since_Admit >= 500 and no valid override code is

Child age in years (calculated accord	ing to birthdate entered): Age is calculated based on the birthdate
2, , , ,	Value not provided imported from the RMS subject information survey. If this is not correct, please change the birthdate below. [Datstat_Dateofbirth]
Question: BIRTHDATE_ENTERED	
Please confirm patient date of I	irth
	Default = [Datstat_Dateofbirth]. Value not provided
Page Break	
Subject age in months: [Age Value not provided	InMonths] = calculated based on birthdate and PICU date
Age group for PedsQL questions:	[NomAge] = calculated PEDSql question set based on age in months.
Value not provided	AgeInMonths < 11 NomAge = I0 "Infant 1-12 months"
NEXT to confirm and continue	AgeInMonths >= 11 & AgeInMonths < 23 NomAge = I1 "Infant 13-24 months"
Collection: CHILD-ASSENT-FORM	AgeInMonths >= 23 & AgeInMonths < 59 NomAge = T "Toddler 2-4 years"
<b>Contains:</b> CHILD_ASSENT_FORM <b>Show if:</b> (NOMAGE = C) or (NOMAGE = TN)	AgeInMonths >= 59 & AgeInMonths < 95 NomAge = YC "Young Child 5-7 years" AgeInMonths >= 95 & AgeInMonths < 155 NomAge = C "Child 8-12 years - eligible for self-report"
	_AgeInMonths >=155 & AgeInMonths < 216 NomAge = TN "Teen 13-18 years - eligible for self-report"
Question: CHILD_ASSENT_FORM	
Scale Summary Code Label Show-If	
1 Yes	
2 No	
Does the child have an assent	orm filled out and on file?
• Yes Value not provi	ded
○ No	
Collection: RC_HOSPITAL Contains: C_DEVICES, RC_MEDS, RC_COMM Show if: (IN_HOSPITAL = 1)	[In_Hospital] = Set to "1" for the Baseline survey, calculated based on status for later timepoints
RC: We're going to start by asking	g you a few questions about the child's medicine and medical devices.
Quanting C DEV//CES	
Question: C_DEVICES	
Chronic Devices	please list any medical devices the child is using. (check all that apply)
5 , 1	Broviac, Hickman, Port-a-cath, PICC
□ 2. Communication aid	
<ul> <li>3. Cystostomy, Foley cather</li> </ul>	ter or intermittent catheterization
🗌 4. Dialysis: hemodialysis, p	eritoneal dialysis
5. Feeding tube, Gastrostor	ny/jejunostomy/OG/NG
□ 6. Hearing Aid	al dialycic These data are found in the variable 'Devices' Table
7. Hemodialysis or peritone	al ulaivis
<ul> <li>8. Mechanical ventilation/Cl</li> <li>9. Oxygen</li> </ul>	
<ul> <li>In the second sec</li></ul>	nternal defibrillator
□ 11. Prostheses or braces	
12. Total parenteral nutritic	n
13. Tracheostomy	
14. Ventricular shunt	
15. Wheelchair	
□ 16. Other	
🗌 17. Other	
□ 18. None	

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Question: PARENT_V Required	PARENT WILLING STUDY
Show if: (NOMAGE ≠ Scale Summary	YA) — —
Code Label Show-If	
1 Yes	
0 No	
	ng to answer questions about your child right now?
O Yes	Terman ( W/W) - Could be observed the could
○ No	If [Parent_Willing_Study] = 0, survey skips to the end
Page Break	
Collection: DEV_DELA Contains: DEVELOPM	
Question: DEVELOP	
Question: DEVELOPM Required	
	DGGLE = 1) or (SELFREPORT_TOGGLE = 1)
Scale Summary Code Label Show-If	
1 Yes	
0 No	
Now we are	going to select the appropriate survey for your child.
	our child best, if you believe your child has a <b>severe physical or mental delay or</b> ease select 'yes' to be directed to the second survey. <b>Value not provided</b>
Page Break	
Collection: FOLLOWU Contains: FUTURE_ST	
ong-term follow-u	eeing to participate in the LAPSE research study. We especially value your commitment to the p aspects of this research. It is likely that other research related to LAPSE and the families E will be designed.
Question: FUTURE_S	TUDIES_D00
Scale Summary	
Code Label Show-If	
1 Yes	
2 No	
May we cont	act you in the future for other potential studies related to LAPSE?
○ Yes	Value not provided
O No	
	ed, please visit our Facebook page to read about updates and outcomes related to our study: ediatric Sepsis Evaluation
Page Break	
	UESTIONS PORT_FS2R, PARENT_REPORT_NOT_FS2R, PARENT_REPORT_MISC LLING_STUDY = 1:[Yes])

Now we're going to ask you some questions about your child's quality of life. We'd like to know how your child has been doing during the **past month**, **BEFORE** he or she became sick and came to the hospital.

Collection: PARENT\_REPORT\_FS2R Contains: FS2R\_TABLE Show if: (FS2R\_TOGGLE = 1) and (IN\_COMA ≠ 1)

Child Functional Status (FS - IIR)

 Question Block: FS2R\_TABLE

 Contains: EATWELL, SLEEPWELL, CONTENT, MOODY, COMMUNICATE, SICK, OCCUPY, LIVELY, CROSS, SLEEPNIGHT, RESPOND,

 DIFFICULT, INTEREST, CRYING

 Scale Summary

 Code Label
 Show-If

 0
 Never or rarely

 1
 Some of the time

 2
 Almost always

Here are some statements that parents have made to describe their children. Thinking about your child during the last ONE Month:

	Never or rarely	Some of the time	Almost always
Did he/she eat well? EATWELL	0	0	0
Did he/she sleep well? SLEEPWELL	0	0	0
Did he/she seem contented and cheerful? CHEERFUL	0	0	0
Did he/she act moody? MOODY	0	0	0
Did he/she communicate what he/she wanted? $COMMUNICA$	TE O	0	0
Did he/she seem to feel sick and tired? ${ m SICK}$	0	0	0
Did he/she occupy him/herself? OCCUPY	0	0	0
Did he/she seem lively and energetic? LIVELY	0	0	0
Did he/she seem unusually irritable and cross?CROSS	0	0	0
Did he/she sleep through the night? SLEEPNIGHT	0	0	0
Did he/she respond to your attention? RESPOND	0	0	0
Did he/she seem unusually difficult? DIFFICULT	0	0	0
Did he/she seem interested in what was going on around him/her? $\underline{INTEREST}$	0	0	0
Did he/she react to little things by crying? $\overrightarrow{CRYING}$	0	0	0

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Collection: PARENT\_REPORT\_NOT\_FS2R Contains: PARENT\_REPORT\_INFANT\_1\_12\_MO, PARENT\_REPORT\_INFANT\_13\_24\_MO, PARENT\_REPORT\_TODLER\_2\_4\_YR, PARENT\_REPORT\_YCHILD\_5\_7\_YR, PARENT\_REPORT\_CHILD\_8\_12\_YR, PARENT\_REPORT\_TEEN\_13\_18\_YR Show if: (FS2R\_TOGGLE = 0) and (IN\_COMA ≠ 1)

#### DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by selecting:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.

Page Break

Collection: PARENT\_REPORT\_INFANT\_1\_12\_MO Contains: P\_I0\_PHYSICAL\_FUNCTION, P\_I0\_PHYSICAL\_SYMPTOMS, P\_I0\_EMOTIONAL, P\_I0\_SOCIAL, P\_I0\_COGNITIVE Show if: (NOMAGE = I0)

In the past ONE month, how much of a problem has your child had with ...

	Physical Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_i0_PF4	Low energy level	0	0	0	0	0
P_i0_PF5	Difficulty participating in active play	0	0	0	0	0
P_i0_PF6	Having hurts or aches	0	0	0	0	0
P_i0_PF7	Feeling tired	0	0	0	0	0
P_i0_PF8	Being lethargic	0	0	0	0	0
P_i0_PF84	Resting a lot	0	0	0	0	0

			SICAL_SYMPTOMS 2510, P_I0_PS11, P_I0_PS12, P_I0_PS13, P_I0_PS14, P_I0_PS15, P_I0_PS16, P_I0_PS17, P_I0_	_PS18
	Scale Summa	ary		
Code	Label	Show-If	f	
0	Never			
1	Almost Never			
2	Sometimes		m	
3	Often			
	Almost Always			

In the past **ONE month**, how much of a **problem** has your child had with ...

	Physical Symptoms	Never	Almost Never	Sometimes	Often	Almost Always
P_i0_PS9	Having gas	0	0	0	0	0
P_i0_PS10	Spitting up after eating	0	0	0	0	0
P_i0_PS11	Difficulty breathing	0	0	0	0	0
P i0 PS12	Being sick to his/her stomach	0	0	0	0	0
P_i0_PS13	Difficulty swallowing	0	0	0	0	0
P_i0_PS14	Being constipated	0	0	0	0	0
P_i0_PS15	Having a rash	0	0	0	0	0
P_i0_PS16	Having diarrhea	0	0	0	0	0
P_i0_PS17	Wheezing	0	0	0	0	0
P_i0_PS18	Vomiting	0	0	0	0	0

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	Scale Summa	ary						
Code	e Label	Show-If						
0	Never							
1	Almost Never							
2	Sometimes Often							
4	Almost Always							
/	In the past (	ONE m	onth, how much of a <b>p</b>	<b>roblem</b> has	your child h	ad with		
	Emotional F	unctior	iing	Never	Almost Never	Sometimes	Often	Almos Alway
i0_E34	Feeling afra	aid or so	cared	0	0	0	0	0
i0_E35	Feeling ang	jry		0	0	0	0	0
i0_E36	Crying or fu	ussing v	vhen left alone	0	0	0	0	0
i0_E37	Difficulty so upset	oothing	himself/herself when	0	0	0	0	0
i0_E38	Difficulty fa	alling as	leep	0	0	0	0	0
i0_E85	Crying or fu	ussing v	while being cuddled	0	0	0	0	0
i0 E39	Feeling sad			0	0	0	0	0
i0E40	Difficulty be or held	eing soo	othed when picked up	0	0	0	0	0
0_E41	Difficulty sl night	eeping	mostly through the	0	0	0	0	0
0_E42	Crying a lot	t		0	0	0	0	0
0_E43	Feeling cra	nky		0	0	0	0	0
0 E44	Difficulty ta	akina na	ps during the day	0	0	0	0	0

	Question Block: P_I0_SOCIAL Contains: P_I0_S53, P_I0_S54, P_I0_S55, P_I0_S56									
	Scale Summa	iry								
Code	Label	Show-If								
0	Never									
1	Almost Never									
2	Sometimes									
3	Often									
4	Almost Always									
	In the past (	ONE m	<b>onth</b> , how much of a <b>p</b>	<b>roblem</b> has	your child ha	ad with				
	Social Func	tioning		Never	Almost Never	Sometimes	Often	Almost Always		
		-						/		
_ <mark>S</mark> 53	Not smiling	at othe	ers	0	0	0	0	0		
_S53 _S54	Not smiling Not laughin			0		0	0	0		

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Page Break

P\_i0\_S56

Question Block: P\_I0\_COGNITIVE Contains: P\_I0\_C66, P\_I0\_C67, P\_I0\_C68, P\_I0\_C69 Scale Summary Code Label Show-If 0 Never 1 Almost Never 2 Sometimes 3 Often 4 Almost Always

Not laughing when cuddled

		Never	Almost Never	Sometimes	Often	Almost Always
P_i0_C66	Not imitating caregivers' actions	0	0	0	0	0
P_i0_C67	Not imitating caregivers' facial expressions	0	0	0	0	0
P_i0_C68	Not imitating caregivers' sounds	0	0	0	0	0
P_i0_C69	Not able to fix his/her attention on objects	0	0	0	0	0

Collection: PARENT\_REPORT\_INFANT\_13\_24\_MO Contains: P\_I1\_PHYSICAL\_FUNCTION, P\_I1\_PHYSICAL\_SYMPTOMS, P\_I1\_EMOTIONAL, P\_I1\_SOCIAL, P\_I1\_COGNITIVE Show if: (NOMAGE = I1)

	ion Block: P_i ins: P_I1_PF4,	
	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
	Almost Always	

_	Physical Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_i1_PF4	Low energy level	0	0	0	0	0
P_i1_PF5	Difficulty participating in active play	0	0	0	0	0
P_i1_PF6	Having hurts or aches	0	0	0	0	0
P_i1_PF7	Feeling tired	0	0	0	0	0
P_i1_PF11	Being lethargic	0	0	0	0	0
P_i1_PF12	Resting a lot	0	0	0	0	0
P_i1_PF13	Feeling too tired to play	0	0	0	0	0
P_i1_PF14	Difficulty walking	0	0	0	0	0
P_i1_PF15	Difficulty running a short distance without falling	0	0	0	0	0
Page B	Jreak					

	Scale Summa	ary
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	

	Physical Symptoms	Never	Almost Never	Sometimes	Often	Almost Always
P_i1_PS18	Having gas	0	0	0	0	0
P_i1_PS19	Spitting up after eating	0	0	0	0	0
P_i1_PS20	Difficulty breathing	0	0	0	0	0
P_i1_PS21	Being sick to his/her stomach	0	0	0	0	0
P_i1_PS22	Difficulty swallowing	0	0	0	0	0
P_i1_PS25	Being constipated	0	0	0	0	0
P_i1_PS26	Having a rash	0	0	0	0	0
P_i1_PS27	Having diarrhea	0	0	0	0	0
P_i1_PS28	Wheezing	0	0	0	0	0
P_i1_PS29	Vomiting	0	0	0	0	0
Page I	Break					

	Scale Summa	ary						
Code	Label	Show-If						
0	Never							
1	Almost Never							
2	Sometimes							
3	Often							
4	Almost Always							
/	In the past (	ONE m	onth, how much of a p	<b>roblem</b> has	your child h	ad with		
	Emotional F	unctior	ning	Never	Almost Never	Sometimes	Often	Almo Alwa
_E49	Feeling afra	aid or so	cared	0	0	0	0	0
_E50	Feeling ang	jry		0	0	0	0	0
E51	Crying or fu	ussing v	vhen left alone	0	0	0	0	0
E52	Difficulty so upset	oothing	himself/herself when	0	0	0	0	0
_E53	Difficulty fa	alling as	leep	0	0	0	0	0
_E119	Crying or fu	ussing v	while being cuddled	0	0	0	0	0
E54	Feeling sad	l		0	0	0	0	0
_E55	Difficulty be or held	eing soo	othed when picked up	0	0	0	0	0
_E56	Difficulty sl night	eeping	mostly through the	0	0	0	0	0
_E57	Crying a lot	t		0	0	0	0	0
_E58	Feeling cra	nky		0	0	0	0	0
E120	Difficulty ta	kina na	aps during the day	0	0	0	0	0

	tion Block: P_ ains: P_I1_S68		AL 71, P_I1_S72, P_I1_S73, P_I1_S70
	Scale Summa	ary	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

#### In the past ONE month, how much of a problem has your child had with ...

	Social Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_i1_S68	Not smiling at others	0	0	0	0	0
P_i1_S71	Not laughing when tickled	0	0	0	0	0
P_i1_S72	Not making eye contact with a caregiver	0	0	0	0	0
P_i1_S73	Not laughing when cuddled	0	0	0	0	0
P_i1_S70	Being uncomfortable around other children	0	0	0	0	0

Page Break

 
 Scale
 Show-If

 0
 Never

 1
 Almost Never

 2
 Sometimes

 3
 Often

 4
 Almost Always

		Never	Almost Never	Sometimes	Often	Almost Always
P_i0_C88	Not imitating caregivers' actions	0	0	0	0	0
P_i0_C89	Not imitating caregivers' facial expressions	0	0	0	0	0
P_i0_C121	Not imitating caregivers' sounds	0	0	0	0	0
P_i0_C90	Not able to fix his/her attention on objects	0	0	0	0	0
P_i1_C122	Not imitating caregivers' speech	0	0	0	0	0
P_i1_C96	Difficulty pointing to his/her body parts when asked	0	0	0	0	0
P_i1_C95	Difficulty naming familiar objects	0	0	$\circ$	0	0
P i1 C97	Difficulty repeating words	0	0	0	0	0
P_i1_C98	Difficulty keeping his/her attention on things	0	0	0	0	0

Collection: PARENT\_REPORT\_TODLER\_2\_4\_YR Contains: P\_T\_PHYSICAL, P\_T\_EMOTIONAL, P\_T\_SOCIAL, SCHOOL\_DAY\_YN, P\_T\_SCHOOL\_DAY, P\_T\_COGNITIVE Show if: (NOMAGE = T)

	Scale Summa		P_T_P5, P_T_P6, P_T_P7, P_T_P8, P_T_P9, P
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

In the past ONE month, how much of a problem has your child had with ...

	Physical Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_T_P3	Walking	0	0	0	0	0
P_T_P4	Running	0	0	0	0	0
P_T_P5	Participating in active play or exercise	0	0	0	0	0
P_T_P6	Lifting something heavy	0	0	0	0	0
P_T_P7	Bathing	0	0	0	0	0
P_T_P8	Helping to pick up his or her toys	0	0	0	0	0
P_T_P9	Having hurts or aches	0	0	0	0	0
P_T_P10	Low energy level	0	0	0	0	0

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Page Break

	ins: P_T_E12, Scale Summa		3, P_	 /'_'_c	10/1-1-
Code	Label	Show-If	F		
0	Never				
1	Almost Never				
2	Sometimes				
3	Often				
4	Almost Always				

In the past ONE month, how much of a problem has your child had with ...

	Emotional Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_T_E12	Feeling afraid or scared	0	0	0	0	0
P_T_E13	Feeling sad or blue	0	0	0	0	0
P_T_E14	Feeling angry	0	0	0	0	0
P_T_E15	Trouble sleeping	0	0	0	0	0
P_T_E16	Worrying	0	0	0	0	0

	tains: P_T_S18, P_T_S19, P_T_S2 Scale Summary	20, F_1_321, F_1_322				
Code	e Label Show-If					
0	Never					
1	Almost Never					
2	Sometimes					
3	Often					
4	Almost					
_	Always					
	In the past <b>ONE month</b> ,	how much of a <b>pr</b> o	oblem has yo	our child had w	ith	1
	Social Functioning	Never	Almost Never	Sometimes	Often	Almost Always
18	Playing with other childre	en 🔿	0	0	0	0
19	Other kids not wanting to with him or her	o play	0	0	0	0
20	Getting teased by other children	0	0	0	0	0
21	Not able to do things tha other children his or her can do		0	0	0	0
22	Keeping up when playing other children	with	0	0	0	0
age E	Break	I				
equir Scale	e Summary					
equir Scale ode L Y	red	ol or daycare? Sc	hoolDay			
equir Scale ode L	red a Summary abel Show-If res No oes your child attend scho	ol or daycare? Sc	hoolDay			
equir Scale ode L Y D	red a Summary abel Show-If res No oes your child attend school ) Yes ) No	ool or daycare? Sc	hoolDay			
equir Scale ode L Y D C D C D C D C D C D C D C D C D C D	red a Summary abel Show-If fes oes your child attend scho ) Yes ) No tion Block: P_T_SCHOOL_DAY rains: P_T_SD24, P_T_SD25, P_T v if: (SCHOOL_DAY_TN = 0:[Yes]	_SD26	hoolDay			
equir Scale ode L Y D C C C B R C C Otto S D C C C Otto S D C C Otto S D C C C C C C C C C C C C C C C C C C	red a Summary abel Show-If fes oes your child attend scho ) Yes ) No back Stion Block: P_T_SCHOOL_DAY tains: P_T_SD24, P_T_SD25, P_T	_SD26	hoolDay			
Ques Code	red a Summary abel Show-If fes oes your child attend scho ) Yes ) No aak stion Block: P_T_SCHOOL_DAY if: (SCHOOL_DAY_YN = 0:[Yes] Scale Summary	_SD26	hoolDay			
quir Gcale Code D C C C C C C C C C C C C C	red a Summary abel Show-If fes oes your child attend scho ) Yes ) No aak stion Block: P_T_SCHOOL_DAY if: (SCHOOL_DAY_YN = 0:[Yes] Scale Summary a Label Show-If	_SD26	hoolDay			
quir Scale ode L Y P D C C C C C C C C C C C C C	red a Summary abel Show-If fes oes your child attend scho ) Yes ) No eak stion Block: P_T_SCHOOL_DAY trains: P_T_SD24, P_T_SD25, P_T if: (SCHOOL_DAY_YN = 0:[Yes]) Scale Summary a Label Show-If Never	_SD26	hoolDay			
equir Scale ode L Y P D C C C C C C C C C C C C C C C C C C	red a Summary abel Show-If fes No oes your child attend scho ) Yes ) No eak stion Block: P_T_SCHOOL_DAY tains: P_T_SD24, P_T_SD25, P_T vif: (SCHOOL_DAY_YN = 0:[Yes]) Scale Summary e Label Show-If Never Almost Never	_SD26	hoolDay			
equir Scale ode L Y D C C Cont Show Code 0 1 2	red summary abel Show-If fes No oes your child attend scho Yes No Pak stion Block: P_T_SCHOOL_DAY tains: P_T_SD24, P_T_SD25, P_T if: (SCHOOL_DAY_YN = 0:[Yes] Scale Summary a Label Show-If Never Almost Never Sometimes	_SD26	hoolDay			
equir Scale ode L Y D C C C C C C C C C C C C C C C C C C	red a Summary abel Show-If fes oes your child attend scho Yes No books P_T_SCHOOL_DAY tains: P_T_SD24, P_T_SD25, P_T wif: (SCHOOL_DAY_YN = 0:[Yes]) Scale Summary blabel Show-If Never Almost Never Sometimes Often Almost	SD26		our child had w		
equir Scale Code L Y P D C C C C C C C C C C C C C C C C C C	red summary abel Show-If fes No oes your child attend scho Yes No eak stion Block: P_T_SCHOOL_DAY tains: P_T_SD24, P_T_SD25, P_T v if: (SCHOOL_DAY_YN = 0:[Yes]) Scale Summary e Label Show-If Never Almost Never Sometimes Often Almost Always	SD26		our child had w	ith Often	Almost Always

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P\_T\_SD25

P\_T\_SD26

Missing school/daycare because of not feeling well

Missing school/daycare to go to the doctor or hospital

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Conta	tion Block: P_ ins: P_T_CF1, if: (HIDE_YN ≠	P_T_CF2	ITIVE 2, P_T_CF3, P_T_CF4, P_T_CF5, P_T_CF6
	Scale Summa	ary	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

*In the past ONE month, how much of a problem has this been for your child...* 

		Never	Almost Never	Sometimes	Often	Almost Always
P_T_CF1	Difficulty keeping his/her attention on things	0	0	0	0	0
P_T_CF2	Difficulty remembering what people tell him/her	0	0	0	0	0
P_T_CF3	Difficulty remembering what he/she just heard	0	0	0	0	0
P_T_CF4	Difficulty thinking quickly	0	0	0	0	0
P_T_CF5	Trouble remembering what he/she was just thinking	0	0	0	0	0
P_T_CF6	Trouble remembering more than one thing at a time	0	0	0	0	0

Collection: PARENT\_REPORT\_YCHILD\_5\_7\_YR Contains: P\_YC\_PHYSICAL, P\_YC\_EMOTIONAL, P\_YC\_SOCIAL, P\_YC\_SCHOOL, P\_YC\_COGNITIVE Show if: (NOMAGE = YC)

Question Block: P\_YC\_PHYSICAL Contains: P\_YC\_P3, P\_YC\_P4, P\_YC\_P5, P\_YC\_P6, P\_YC\_P7, P\_YC\_P8, P\_YC\_P9, P\_YC\_P10 Scale Summary Code Label Show-If Never 0 1 Almost Never 2 Sometimes 3 Often 4 Almost Always

	Physical Functioning	Never	Almost Never	Sometimes	Often	Almost Always	
P_YC_P3	Walking more than one block	0	0	0	0	0	
P_YC_P4	Running	0	0	0	0	0	
P_YC_P5	Participating in sports activity or exercise	0	0	0	0	0	
P_YC_P6	Lifting something heavy	0	0	0	0	0	
P_YC_P7	Taking a bath or shower by him or herself	0	0	0	0	0	
P_YC_P8	Doing chores, like picking up his or her toys	0	0	0	0	0	
P_YC_P9	Having hurts or aches	0	0	0	0	0	
P_YC_P10	Low energy level	0	0	0	0	0	
Page Break							

	Scale Summa	ary
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	

In the past **ONE month**, how much of a **problem** has your child had with ...

	Emotional Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_YC_E12	Feeling afraid or scared	0	0	0	0	0
P_YC_E13	Feeling sad or blue	0	0	0	0	0
P_YC_E14	Feeling angry	0	0	0	0	0
P_YC_E15	Trouble sleeping	0	0	0	0	0
P_YC_E16	Worrying about what will happen to him or her	0	0	0	0	0

#### Page Break

 Scale
 Show-If

 0
 Never

 1
 Almost Never

 2
 Sometimes

 3
 Often

 4
 Almost

 Almost
 Almost

In the past ONE month, how much of a problem has your child had with ...

	Social Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_YC_S18	Getting along with other children	0	0	0	0	0
P_YC_S19	Other kids not wanting to be his or her friend	0	0	0	0	0
P_YC_S20	Getting teased by other children	0	0	0	0	0
P_YC_S21	Not able to do things that other children his or her age can do	0	0	0	0	0
P_YC_S22	Keeping up when playing with other children	0	0	0	0	0
Daga P	brank					

	tion Block: P_ ains: P_YC_SC		)OL _SC28, P_YC_SC29, P_YC_SC30, P_YC_SC31
	Scale Summa	ary	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

#### In the past ONE month, how much of a problem has your child had with ...

	School Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_YC_SC27	Paying attention in class	0	0	0	0	0
	Forgetting things	0	0	0	0	0
P_YC_SC29	Keeping up with school activities	0	0	0	0	0
P_YC_SC30	Missing school because of not feeling well	0	0	0	0	0
P_YC_SC31	Missing school to go to the doctor or hospital	0	0	0	0	0

#### Page Break

 Scale Summary

 Code Label
 Show-If

 0
 Never

 1
 Almost Never

 2
 Sometimes

 3
 Often

4 Almost Always

In the past ONE month, how much of a problem has this been for your child...

		Never	Almost Never	Sometimes	Often	Almost Always
P_YC_CF1	Difficulty keeping his/her attention on things	0	0	0	0	0
P_YC_CF2	Difficulty remembering what people tell him/her	0	0	0	0	0
P_YC_CF3	Difficulty remembering what he/she just heard	0	0	0	0	0
P_YC_CF4	Difficulty thinking quickly	0	0	0	0	0
P_YC_CF5	Trouble remembering what he/she was just thinking	0	0	0	0	0
P_YC_CF6	Trouble remembering more than one thing at a time	0	0	0	0	0

Collection: PARENT\_REPORT\_CHILD\_8\_12\_YR Contains: P\_C\_PHYSICAL, P\_C\_EMOTIONAL, P\_C\_SOCIAL, P\_C\_SCHOOL, P\_C\_COGNITIVE Show if: (NOMAGE = C)

	tion Block: P_ ains: P_C_P3, I	
	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	

	Physical Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_C_P3	Walking more than one block	0	0	0	0	0
P_C_P4	Running	0	0	0	0	0
P_C_P5	Participating in sports activity or exercise	0	0	0	0	0
P_C_P6	Lifting something heavy	0	0	0	0	0
P_C_P7	Taking a bath or shower by him or herself	0	0	0	0	0
P_C_P8	Doing chores around the house	0	0	0	0	0
P_C_P9	Having hurts or aches	0	0	0	0	0
P C P10	Low energy level	0	0	0	0	0
Page E	3reak					

	tion Block: P_ ains: P_C_E12,	
	Scale Summa	ary
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	

In the past ONE month, how much of a problem has your child had with ...

	Emotional Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_C_E12	Feeling afraid or scared	0	0	0	0	0
P_C_E13	Feeling sad or blue	0	0	0	0	0
P_C_E14	Feeling angry	0	0	0	0	0
P_C_E15	Trouble sleeping	0	0	0	0	0
P_C_E16	Worrying about what will happen to him or her	0	0	0	0	0

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Page Break

 Scale
 Show-If

 0
 Never

 1
 Almost Never

 2
 Sometimes

 3
 Often

 4
 Almost

 4
 Almost

	Social Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_C_S18	Getting along with other children	0	0	0	0	0
P_C_S19	Other kids not wanting to be his or her friend	0	0	0	0	0
P C S20	Getting teased by other children	0	0	0	0	0
P_C_S21	Not able to do things that other children his or her age can do	0	0	0	0	0
P_C_S22	Keeping up when playing with other children	0	0	0	0	0
Page E	Break					

	tion Block: P_ ains: P_C_SC2		)L C28, P_C_SC29, P_C_SC30, P_C_SC
	Scale Summa	ary	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

In the past **ONE month**, how much of a **problem** has your child had with ...

	School Functioning	Never	Almost Never	Sometimes	Often	Almost Always		
P_C_SC27	Paying attention in class	0	0	0	0	0		
P_C_SC28	Forgetting things	0	0	0	0	0		
P_C_SC29	Keeping up with school activities	0	0	0	0	0		
P_C_SC30	Missing school because of not feeling well	0	0	0	0	0		
P_C_SC31	Missing school to go to the doctor or hospital	0	0	0	0	0		
Page E	Page Break							

 Question Block: P\_C\_COGNITIVE

 Contains: P\_C\_CF1, P\_C\_CF2, P\_C\_CF3, P\_C\_CF4, P\_C\_CF5, P\_C\_CF6

 Show if: (HIDE\_YN ≠ 1)

 Scale Summary

 Code Label
 Show If

 0
 Never
 1

 1
 Almost Never
 2

 2
 Sometimes
 3

 3
 Often
 4

 4
 Almost Always
 4

In the past ONE month, how much of a problem has this been for your child...

_		Never	Almost Never	Sometimes	Often	Almost Always
P_C_CF1	Difficulty keeping his/her attention on things	0	0	0	0	0
P_C_CF2	Difficulty remembering what people tell him/her	0	0	0	0	0
P_C_CF3	Difficulty remembering what he/she just heard	0	0	0	0	0
P_C_CF4	Difficulty thinking quickly	0	0	0	0	0
P_C_CF5	Trouble remembering what he/she was just thinking	0	0	0	0	0
P_C_CF6	Trouble remembering more than one thing at a time	0	0	0	0	0

Collection: PARENT\_REPORT\_TEEN\_13\_18\_YR Contains: P\_TN\_PHYSICAL, P\_TN\_EMOTIONAL, P\_TN\_SOCIAL, P\_TN\_SCHOOL, P\_TN\_COGNITIVE Show if: (NOMAGE = TN)

	tion Block: P_ ains: P_TN_P3,		ICAL 4, P_TN_P5, P_TN_P6, P_TN_P7, P_TN_P8, P_TN_P9, P_TN_P1
	Scale Summa	ary	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

In the past **ONE month**, how much of a **problem** has your child had with ...

	Physical Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_TN_P3	Walking more than one block	0	0	0	0	0
P_TN_P4	Running	0	0	0	0	0
P_TN_P5	Participating in sports activity or exercise	0	0	0	0	0
P_TN_P6	Lifting something heavy	0	0	0	0	0
P_TN_P7	Taking a bath or shower by him or herself	0	0	0	0	0
P_TN_P8	Doing chores around the house	0	0	0	0	0
P_TN_P9	Having hurts or aches	0	0	0	0	0
P_TN_P10	Low energy level	0	0	0	0	0

	tion Block: P_ nins: P_TN_E12		TIONAL E13, P_TN_E14, P_TN_E15, P_TN
	Scale Summa	ary	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

	Emotional Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_TN_E12	Feeling afraid or scared	0	0	0	0	0
P_TN_E13	Feeling sad or blue	0	0	0	0	0
P_TN_E14	Feeling angry	0	0	0	0	0
P_TN_E15	Trouble sleeping	0	0	0	0	0
P_TN_E16	Worrying about what will happen to him or her	0	0	0	0	0
Daga F	Prost					

Page Break

	tion Block: P_ ins: P_TN_S18	
	Scale Summa	ary
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
	Almost Always	

In the past ONE month, how much of a problem has your child had with ...

	Social Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_TN_S18	Getting along with other teens	0	0	0	0	0
P_TN_S19	Other teens not wanting to be his or her friend	0	0	0	0	0
P_TN_S20	Getting teased by other teens	0	0	0	0	0
P_TN_S21	Not able to do things that other teens his or her age can do	0	0	0	0	0
P_TN_S22	Keeping up with other teens	0	0	0	0	0

Page Break

	Scale Summa	arv
	Label	Show-If
		5110W-11
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	

In the past ONE month, how much of a problem has your child had with ...

	School Functioning	Never	Almost Never	Sometimes	Often	Almost Always
P_TN_SC27	Paying attention in class	0	0	0	0	0
P_TN_SC28	Forgetting things	0	0	0	0	0
P_TN_SC29	Keeping up with school activities	0	0	0	0	0
P_TN_SC30	Missing school because of not feeling well	0	0	0	0	0
P_TN_SC31	Missing school to go to the doctor or hospital	0	0	0	0	0
Daga	Prost					

Conta	tion Block: P_ ains: P_TN_CF: if: (HIDE_YN #	1, P_TN_0	NITIVE CF2, P_TN_CF3, P_TN_CF4, P_TN_CF5, P_TN_CF6
	Scale Summa	ary	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		

*In the past ONE month, how much of a problem has this been for your child...* 

	Never	Almost Never	Sometimes	Often	Almost Always
P_TN_CF1 Difficulty keeping his/her attention on things	0	0	0	0	0
P_TN_CF2 Difficulty remembering what people te him/her	I 0	0	0	0	0
P_TN_CF3 Difficulty remembering what he/she ju heard	st 🛛	0	0	0	0
P_TN_CF4 Difficulty thinking quickly	0	0	0	0	0
P_TN_CF5 Trouble remembering what he/she was just thinking	0	0	0	0	0
P_TN_CF6 Trouble remembering more than one thing at a time	0	0	0	0	0
Collection: PARENT_REPORT_MISC Contains: PERSONALITY_INVENTORY, BRIEF_SYMPTOM DISPOSITION_RESOURCES, CONTACTINFO, COMMENTS Page Break	_INVENTORY, FAMI	LY_ASSESSMEN	I_DEVICE, MEDIC	CAL_DEVICES_N	_MEDICATIONS,

Question Block: BSI\_TABLE Contains: FAINT, NO\_INTEREST, NERVOUS, CHEST\_PAINS, LONELY, TENSE, NAUSEA, BLUE, SCARED Scale Summary Code Label Show-If 1 Not At All 2 А Little Bit 3 Moderately 4 Quite Â Bit 5 Extremely

Remember, these questions are about YOU. Below is a list of problems people sometimes have. Please read each one carefully and select the answer that best describes how much that problem has distressed or bothered YOU DURING THE PAST 7 DAYS, INCLUDING TODAY.

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#### HOW MUCH WERE YOU DISTRESSED BY:

		Not At All	A Little Bit	Moderately	Quite A Bit	Extremely
FAINT	Faintness or dizziness	$\bigcirc$	0	0	0	0
NO_INTEREST	Feeling no interest in things	$\bigcirc$	0	0	0	0
NERVOUS	Nervousness or shakiness inside	$\bigcirc$	0	0	0	0
CHEST_PAINS	Pains in heart or chest	$\bigcirc$	0	0	0	0
LONELY	Feeling lonely	$\bigcirc$	0	0	0	0
TENSE	Feeling tense or keyed up	$\bigcirc$	0	0	0	0
NAUSES	Nausea or upset stomach	0	0	0	0	0
BLUE	Feeling blue	$\bigcirc$	0	0	0	0
SCARED	Suddenly scared for no reason	0	0	0	0	0
Bago B	Brook					

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	tion Block: B ains: BREATH	
	Scale Summ	
Code	Label	Show-If
1	Not At All	
2	A Little Bit	
3	Moderately	
4	Quite A Bit	
5	Extremely	

Below are some more problems people sometimes have. Please read each one carefully and select the response that best describes how much that problem has distressed or bothered **YOU** DURING THE **PAST 7 DAYS**, INCLUDING TODAY.

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# HOW MUCH WERE YOU DISTRESSED BY:

		Not At All	A Little Bit	Moderately	Quite A Bit	Extremely
BREATH_TRBL	Trouble getting your breath	0	0	0	0	0
WORTHLES	Feelings of worthlessness	0	0	0	0	0
PANIC	Spells of terror or panic	0	0	0	0	0
NUMB	Numbness or tingling in parts of your body	0	0	0	0	0
HOPELES	Feeling hopeless about the future	0	0	0	0	0
RESTLES	Feeling so restless you couldn't sit still	0	0	0	0	0
WEAK	Feeling weak in parts of your body	0	0	0	0	0
FEARFUL	Feeling fearful	0	0	0	0	0

Collection: FAMILY\_ASSESSMENT\_DEVICE Contains: FA\_GROUP

# Question Block: FA\_GROUP Contains: FA\_MISUNDER, FA\_SUPPORT, FA\_SADNES, FA\_ACCEPT, FA\_AVOID, FA\_EXPRES, FA\_BADFEEL, FA\_WEACCPT, FA\_DECISN\_PROB, FA\_PROB\_SOLVE, FA\_GETALNG\_NO, FA\_CONFIDE Scale Summary Code Label Show-If 1 Strongly Agree Agree</td

Below, you can see a number of statements about families. Read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family. Each statement has four (4) possible responses:

Strongly agree: Choose this answer if you feel that the statement describes your family very accurately.
 Agree: Choose this answer if you feel that the statement describes your family for the most part.
 Disagree: Choose this answer if you feel that the statement does not describe your family for the most part.
 Strongly disagree: Choose this answer if you feel that the statement does not describe your family at all.

Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have a hard time deciding what to answer, go with your first reaction. Please answer every statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Planning family activities is difficult because we misunderstand each other $FA\_MISUNDER$	0	0	0	0
In times of crisis we can turn to each other for support. $FA\_SUPPORT$	0	0	0	0
We cannot talk to each other about the sadness we feel. $FA\_SADNES$	0	0	0	0
Individuals are accepted for what they are $FA\_ACC$	EPT	0	0	0
We avoid discussing our fears and $concerns_A\_AVC$	DID O	0	0	0
We can express feelings to each other $FA\_EXPRE$	s o	0	0	0
There are lots of bad feelings in the family $FA\_BAI$	DFEEL	0	0	0
We feel accepted for what we are. $FA_WEA$	ССРТ	0	0	0
Making decisions is a problem for our family. $FA_DF$	CISN_PR	OBO	0	0
We are able to make decisions about how to solve problems. $FA\_PROB\_SOLVE$	0	0	0	0
We don't get along well together $FA\_GETALNG$	NOO	0	0	0
We confide in each other.FA CONFIDE	0	0	0	0

Collection: CONTACTINFO Contains: ONLINE\_OR\_PHONE, DATSTAT\_HOMEPHONE, DATSTAT\_MOBILEPHONE, CALL\_TIME, DATSTAT\_EMAIL

Thank you for agreeing to be part of our study!

We will be following up with you when your child is out of the hospital and would like to know the best way to contact you to do future surveys.

lequired		
Scale Summary		
ode Label	Show-If	
Online (web-based survey)		
Telephone Interview		
Text Message (web-based surve	y)	
<ul> <li>Online (web-based sur</li> <li>Telephone Interview</li> <li>Text Message (web-based web-based webased web-based web-based web-based web</li></ul>	" UNLINE_OR	<b>C_PHONE</b>
uestion: DATSTAT_HOMEPHONE		
Please enter the phone nu	umber we should call to cor	ntact you in the future, area code first
(XXX-	xxx-xxxx). Value not p	provided
	voit voit value not p	provided
equired how if: (ONLINE_OR_PHONE = 3:[T		
equired how if: (ONLINE_OR_PHONE = 3:[T ] if your survey preference the text messages. uestion: CALL_TIME inimum checks: 1 aximum checks: 3	is "text message" please e	nter the mobile phone number that should receive
equired how if: (ONLINE_OR_PHONE = 3:[T] if your survey preference the text messages. uestion: CALL_TIME inimum checks: 1 aximum checks: 3	is "text message" please e elephone Interview])	enter the mobile phone number that should receive
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<pre>equired how if: (ONLINE_OR_PHONE = 3:[T ) if your survey preference the text messages. uestion: CALL_TIME inimum checks: 1 aximum checks: 3 how if: (ONLINE_OR_PHONE = 2:[T ) What is the best time to co morping (Pam-12, page)</pre>	is "text message" please e elephone Interview]) all you?	enter the mobile phone number that should receive Value not provided
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<pre>equired how if: (ONLINE_OR_PHONE = 3:[T if your survey preference the text messages. uestion: CALL_TIME inimum checks: 1 aximum checks: 3 how if: (ONLINE_OR_PHONE = 2:[T What is the best time to c morning (9am-12 noo afternoon (12 noon to evening (after 5pm but)</pre>	is "text message" please e elephone Interview]) call you? n) 5pm) <b>Value not provi</b>	enter the mobile phone number that should receive Value not provided
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the text messages.	is "text message" please e elephone Interview]) call you? n) 5pm) <b>Value not provi</b> it before 9pm)	ided

Collection: INTERVAL_MEDICAL_ACTIVITY
Contains: ER_VISIT, HOSP, T_CALLS, PLANNED_VISIT, UNPLANNED_VISIT_YN, UNPLANNED_VISIT
<b>Show if:</b> (IN HOSPITAL $\neq$ 1) and (HIDE YN $\neq$ 1)

Medical Activity Since Last Survey							
Question: ER_VISIT							
☑ In the past 3 months, how many times did your child go to the emergency room? (Your best estimate is fine.) EmergRoomVisits							
Enter number (0-15)							
Question: HOSP							
$\square$ In the past 3 months, how many times did your child spend one night or more in the hospital? (Your best estimate is fine). HospVisits							
Enter number (0-15)							
Question: T_CALLS							
In the past 3 months, how many times did you call the office of a doctor or medical professional regarding your child? (Your best estimate is fine.)							
Enter number (0-100) Value not provided							
Page Break							

Question: PLANNED_VISIT		
Scale Summary		
Code	Label	Show-If
0	None	
1	1 to 3 visits	
2	4 to 6 visits, or	
3	More than 6 visits?	

Think about all the doctor's offices and clinics your child visited for health care in the last 3 months. In total, about how many *planned follow-up visits* has (he/she) had? (Your best estimate is fine.)

**DEFINITION:** A **planned visit** is one where your child is usually not sick. These are visits the doctor asks your child to come to. It's a regular check-up or follow-up visit for your child to see how he/she is doing.

Was it: PLANNED VISIT

- None
- $^{\circ}$  1 to 3 visits
- $^{\circ}$  4 to 6 visits, or
- More than 6 visits?

Ques	tion: l	UNPLANN
		UNPLANN mmary
Code	Label	Show-If
0	No	
1	Yes	

During the last 3 months, has your child had any unplanned visits to a doctor's office or clinic ?

**DEFINITION: Unplanned visits** are visits that occur because your child gets sick and you decide you want the doctor to see him/her so you call for an appointment or go to a walk-in clinic where you don't need an appointment.

• No UNPLANNED\_VISIT\_YN

<sup>O</sup> Yes



\_\_\_\_\_

How many *unplanned visits* were there during the last 3 months? (Your best estimate is fine.) Was it:

- O None
- None
   1 to 3 visits
   UNPLANNED\_VISIT
- 4 to 6 visits, or
- More than 6 visits
- Not sure

Show if: (CHILDAGE_CONSENT_INTEGER < 18) and ((DEVELOPMENTAL_DELAY_IMPORT = 1) or (CHILD18_CONSENT_FORM         = 1))         Scale Summary         Code Label Show-If         1       Yes         0       No         Image: State Summary         Code Label Show-If         1       Yes         0       No         Image: State Summary         Okar         Image: State Summary         Okar         Image: State Summary         Image: State	Question: PARENT_WILLING_STUDY Required
Secies Summary         Code (Label Show-IF)         I Yes         Are you willing to answer questions about your child right now?         Yes       PARENT_WILLING_STUDY         No         Question: YOUNG_ADULT_WILLING_STUDY         Required         Show ff (SELF 18 ELGIBLE = 1) and (CHILDAGE_CONSENT_INTEGER >= 18)         Secies Summary         Code (Label Show-If)         I Yes         Value not provided         Page Break         Note:         Code (Label Show-If)         I Yes         Value not provided         Page Break         Note:         Code Label Show-If         I Yes         Sold Summary         Code Label Show-If         I Yes         Sold Summary         Code Label Show-If         I Yes         D Do you think your child will be able to answer questions in the child self-report sections?         No         Code Label Show-If         Ves         Acto Page Break         Question: TOO_ILL         Show ff (CHILDCOMP         Show ff (CHILDCOMP         Show ff (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)) </td <td>Show if: (CHILDAGE_CONSENT_INTEGER &lt; 18) and ((DEVELOPMENTAL_DELAY_IMPORT = 1) or (CHILD18_CONSENT_FORM</td>	Show if: (CHILDAGE_CONSENT_INTEGER < 18) and ((DEVELOPMENTAL_DELAY_IMPORT = 1) or (CHILD18_CONSENT_FORM
I       Yes         ☑       Are you willing to answer questions about your child right now?         ○       Yes         ○       No             Image: Control of the standard of the s	Scale Summary
Image: Second Secon	
Yes       PARENT_WILLING_STUDY         Question: YOUNG, ADULT_WILLING_STUDY         Required         State Summary         Code Label Show-IT         0       No         Is the patient willing to participate in the study?         Yes       Value not provided         Page Break         Note: these questions apply to you and how you're feeling.         Question: CHILDCOMP         Required         Show iff (SELF_18, WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)         Scale Summary         Code Label Show-IT         0       No         Page Break         Moto Page Break         Moto Page Break         Image Break         I	
○ No         Question: YOUNG_ADULT_WILLING_STUDY         Scale Summary         Scale Summary         Code Label Show-If         1       Yes         ∨ Yes         Value not provided         Page Break         Note: these questions apply to you and how you're feeling.         Image: Code Label Show-If         0       No         Page Break         Note: these questions apply to you and how you're feeling.         Image: Code Label Show-If         0       No         Stow If: (SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)         Scale Summary         Code Label Show-If         0       No         Page Break         Image: Show If: (CHILDCOMP         Stow If: (CHILDCOMP         Yes         Auto Page Break         Image: Show If: (CHILDCOMP         Yes         Auto Page Break         Image: Code Label Show-If         Image: Too_ILL         Mommary         Image: Code Label Show-If         Image: Code Label Show-If         Image: Code Label Show-If         Image: Code Label Show-If         Image: Code Label Show-If <td< td=""><td>Are you willing to answer questions about your child right now?</td></td<>	Are you willing to answer questions about your child right now?
Question: CHILDCOMP         Yes         O         No         To sele Summary         Code Label Show-IF         0         No           Is the patient willing to participate in the study?            Yes           Page Break       Note: these questions apply to you and how you're feeling.           Question: CHILDCOMP       Required       Show if (SELF_18, WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)       Scale Summary       Code Label Show-IF       0     No       1     Yes       Image: Do you think your child will be able to answer questions in the child self-report sections?        No     CHILDCOMP       Yes     No       Image: Do you think your child will be able to answer questions in the child self-report sections?        No     CHILDCOMP       Yes     Yes                (Self Summary Code Label Show-IF in the study is and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))              Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1) and              (Self Summary Code Label Show-IF in the origin and (TOO_1LL = 0:[NO]) and (SELF_UNDER18_PARENT_WILLING = 1) and	
Isquired         Show ff (SELF_18_ELICIBLE = 1) and (CHILDAGE_CONSENT_INTEGER >= 18)         Scale Summary         Code Label Show-H         1       Yes         Ves       Value not provided         No         Page Break         Note: these questions apply to you and how you're feeling.         Question: CHILDCOMP         Required         Show ff (SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)         Scale Summary         Code Label Show-H         0       No         Page Break         Image: State Summary         Code Label Show-H         0       No         CHILDCOMP         Required         Show ff (CHILDCOMP         Yes         No         CHILDCOMP         Yes         No         CHILDCOMP         Yes         Auto Page Break         Image: Show-H         Image: Show-H         1       Yes         Image: Show-H         Image: Show-H         Image: Show-H         Image: Show-H         Image: Show-H         Image: Show-H         Imag	() NO
Brow If (SELF_18_ELIGIBLE = 1) and (CHILDAGE_CONSENT_INTEGER >= 18)         Scale Summary         Code Label Show-If         1       Yes         No    Page Break           No    Page Break        No    Page Break Note: these questions apply to you and how you're feeling.          Question: CHILDCOMP         Required         Show if: (SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)    Scale Summary Code Label Show-If          No    Page Break No        Page Break     Question: CHILDCOMP        Yes       Auto Page Break     Question: TOO_ILL          Required         Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)))          Scale Summary         Code Label Show-If         0       No         Image: Code Label Show-IF         0       No         1       <	
Image: Show-If         Image: Image: Show-If         Image: Image: Show-If         Image:	
I       Yes         I       Is the patient willing to participate in the study?         ○       Yes         No       Page Break         Note: these questions apply to you and how you're feeling.         Question: CHILDCOMP       State Summary         Scale Summary       State Summary         Image: State Summary       State Sum	
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No         Page Break         Note: these questions apply to you and how you're feeling.         Question: CHILDCOMP         Required         Scale Summary         Code Label Show-IF         0       No         Child too Unit your child will be able to answer questions in the child self-report sections?         No       CHILDCOMP         Question: TOO_ILL         Required         Show if: (CHILDCOMP         Yes         Auto Page Break         Question: TOO_ILL         Required         Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)))         Scale Summary         Code Label Show-IF         0       No         I yes         I yes         I yes         I yes         Mo         Question: CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDASENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDASENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDASENT	
Page Break         Note: these questions apply to you and how you're feeling.         Question: CHILDCOMP         Scale Summary         Code Label Show-If         0       No         1       Yes         Auto Page Break         Question: TOO_ILL         Required         Show if (CHILDCOMP         Yes         Auto Page Break         Question: TOO_ILL         Required         Show if (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))         Scale Summary         Code Label Show-If         0       No         Code Label Show-If         0       Yes         Auto Page Break         Question: TOO_ILL         Required         Show if (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)))         Scale Summary         O       No         1       Yes         Po_ O_ILLL         Question: CHILD_ASSENT         Required         Show if (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDCAMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDCAMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1	
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Scale Summary         Code Label Show-If         O No         I Yes         Do you think your child will be able to answer questions in the child self-report sections?         No       CHILDCOMP         Auto Page Break         Question: TOO_ILL Required         Scale Summary         Code Label Show-If         0         0         Yes    Question: TOO_ILL          Required         Scale Summary         Out this do the survey?         No         Yes    TOO_ILL          Required             Question: TOO_ILL         Required         Scale Summary         O         No         Yes             I yes             Question: CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
Code Label Show-If         0         No         No         Or you think your child will be able to answer questions in the child self-report sections?         No         CHILDCOMP         Yes         Auto Page Break         Question: TOO_ILL Required Show if (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))         Scale Summary         Code Label Show-If         No         Yes             Is your child too ill to do the survey?         No         Yes             Ves             Is your child too ill to do the survey?         No         Yes             Ves             Ves             Yes             No         Yes             Yes                No         Yes             Yes                Yes             Code Label Show.IT <t< td=""><td>Show if: (SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)</td></t<>	Show if: (SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)
O       No         1       Yes         Do you think your child will be able to answer questions in the child self-report sections?         No       CHILDCOMP         Yes         Auto Page Break         Question: TOO_ILL Required Show iff (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1)))         Scale Summary Code Label Show-If 0         No         Yes         I yes         No         TOO_ILL         Question: CHILD_ASSENT Required Show iff COMELDECOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18) Scale Summary Code Label Show-If 0         Yes	
Do you think your child will be able to answer questions in the child self-report sections?         No       CHILDCOMP         Yes         Auto Page Break         Question: TOO_ILL Required Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))         Scale Summary Code Label Show-If 0 No         I       Yes         I       Yes         No       TOO_ILL         Question: CHILD_ASSENT Required Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
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Yes         Auto Page Break         Question: TOO_ILL Required Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))         Scale Summary Code Label Show-If 0 No         O No         1 Yes         Is your child too ill to do the survey?         ○ No         Yes         Code Label Show-If         ○ No         1 Yes         Is your child too ill to do the survey?         ○ No         ○ Yes         TOO_ILL         Question: CHILD_ASSENT Required Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
Auto Page Break         Question: TOO_ILL Required Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))         Scale Summary         Code Label Show-If         0       No         1       Yes         Is your child too ill to do the survey?         No         Yes         TOO_ILL         Question: CHILD_ASSENT Required Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
Question: TOO_ILL Required Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))         Scale Summary Code Label Show-If 0 No 1 Yes         Is your child too ill to do the survey?         No Yes         TOO_ILL         Question: CHILD_ASSENT Required Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
Required         Show if: (CHILDCOMP = 1:[Yes]) and ((SELF_18_WILLING = 1) or (SELF_UNDER18_PARENT_WILLING = 1))         Scale Summary         Code Label Show-If         0       No         1       Yes         Is your child too ill to do the survey?         No         Yes         Ves         TOO_ILL         Yes         Show if: (CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
Scale Summary         Code Label Show-If         0       No         1       Yes         No         Yes         TOO_ILL         Question: CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	Required
Code Label Show-If         0       No         1       Yes         No       TOO_ILL         Question: CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
1       Yes         Is your child too ill to do the survey?         No         Yes         TOO_ILL             Question: CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	Code Label Show-If
Is your child too ill to do the survey?         No         Yes         TOO_ILL         Question: CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
No       Yes         Orginal       Yes         Question: CHILD_ASSENT         Required         Show if: (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
Yes Ves Ves Ves Ves Ves Ves Ves Ves Ves V	
Required         Show if; (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
Required         Show if; (CHILDCOMP = 1:[Yes]) and (TOO_ILL = 0:[No]) and (SELF_UNDER18_PARENT_WILLING = 1) and (CHILDAGE_CONSENT_INTEGER < 18)	
(CHILDAGE_CONSENT_INTEGER < 18) Scale Summary Code Label Show-If 0 No 1 Yes	Required
Code     Label     Show-If       0     No       1     Yes	
0 No 1 Yes	
1 Yes	
Is your child willing to answer questions about him/herself?	
	Is your child willing to answer questions about him/herself?
O No O Yes CHILD_ASSENT	

Collection: SELF\_REPORT\_CHILD\_8\_12\_YR Contains: S\_C\_PHYSICAL, S\_C\_EMOTIONAL, S\_C\_SOCIAL, S\_C\_COGNITIVE Show if: (NOMAGE = C)

	tion Block: S_ ains: S_C_P3, :	
	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	

Thinking about how you are doing **TODAY**, how much of a **problem** has this been for you ...

S	C	_P3
S	C	_P4
S	C	_P5
S	C	_P6
S	C	_P7
S	C	_P8
S	C	_ <b>P</b> 9
S	C	_P1
		Pa

			Almost			Almost	
	About My Health and Activities	Never	Never	Sometimes	Often	Always	
_P3	It is hard for me to walk more than one block	0	0	0	0	0	
_P4	It is hard for me to run	0	0	0	0	0	
_P5	It is hard for me to do sports activity or exercise	0	0	0	0	0	
_P6	It is hard for me to lift something heavy	0	0	0	0	0	
_P7	It is hard for me to take a bath or shower by myself	0	0	0	0	0	
<u>P8</u>	It is hard for me to do chores around the house	0	0	0	0	0	
_ <b>P9</b>	I hurt or ache	0	0	0	0	0	
P10	I have low energy	0	0	0	0	0	
Page Break							

	ains: S_C_E12, Scale Summa	
	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
	Almost Always	

	About My Feelings	Never	Almost Never	Sometimes	Often	Almost Always
S_C_E12	I feel afraid or scared	0	0	0	0	0
S_C_E13	I feel sad or blue	0	0	0	0	0
S_C_E14	I feel angry	0	0	0	0	0
<b>S_C_E15</b>	I have trouble sleeping	0	0	0	0	0
S_C_E16	I worry about what will happen to me	0	0	0	0	0

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Question Block: S\_C\_SOCIAL Contains: S\_C\_S18, S\_C\_S19, S\_C\_S20, S\_C\_S21, S\_C\_S22 Scale Summary Code Label Show-If 0 Never 1 Almost Never 2 Sometimes 3 Often 4 Almost Always

Thinking about how you are doing **TODAY**, how much of a **problem** has this been for you ... Т

Т

\_\_\_\_\_

	How I Get Along with Others	Never	Almost Never	Sometimes	Often	Almost Always
S_C_S18	I have trouble getting along with other kids	0	0	0	0	0
S_C_S19	my friend	0	0	0	0	0
S_C_S20	Other kids tease me	0	0	0	0	0
S_C_S21	I cannot do things that other kids my age can do	0	0	0	0	0
S_C_S22	It is hard to keep up when I play with other kids	0	0	0	0	0

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Ques	tion: S_C_SC2	7	
	Scale Summa	iry	
Code	Label	Show-If	
0	Never		
1	Almost Never		
2	Sometimes		
3	Often		
4	Almost Always		
	It is hard to Never Almost N Sometim Often Almost A	Never nes	attention in class S_C_SC27
Ques	tion: S_C_SC28		1
Carda	Scale Summa	-	
Code 0	Label	Show-If	-
1	Never		
L	Almost Never		
2 3	Sometimes Often		
4	Almost Always		
	I forget thin Never Almost N Sometim Often Almost A	Never nes	S_C_SC28
Ques	tion: S_C_SC2		1
	Scale Summa	-	
L	Label	Show-If	•
0	Never		•
1	Almost Never		•
2	Sometimes		•
3	Often		•
4	Almost Always		
	I have trou <sup>&gt;</sup> Never	ble kee	eping up with my schoolwork

- Almost Never S\_C\_SC29
- O Sometimes
- ° Often
- <sup>O</sup> Almost Always

Quest	tion: S_C_SC3	0
_	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	
/ 1	miss scho	ol beca
(	Never	
(	AIIIIOSUI	
	Sometin	nes
	Often	
(	D Almost A	Always
-		
Quest	tion: S_C_SC3 Scale Summa	
Code	Label	Show-If
0	Never	0.1017 11
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	
/ I	miss scho	ol to a
	_	or to g
(	Nevel	lovor
	<sup>o</sup> Sometin	
0		les
(	Oiten	lwavs
	Annost	Alway5
Page Bi	reak	

	Scale Summa	iry
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost Always	

	Cognitive Fatigue	Never	Almost Never	Sometimes	Often	Almost Always
S_C_CF1	It is hard for me to keep my attention on things	0	0	0	0	0
S_C_CF2	It is hard for me to remember what people tell me	0	0	0	0	0
S_C_CF3	It is hard for me to remember what I just heard	0	0	0	0	0
S_C_CF4	It is hard for me to think quickly	0	$\bigcirc$	$\bigcirc$	0	0
S_C_CF5	I have trouble remembering what I was just thinking	0	0	0	0	0
S_C_CF6	I have trouble remembering more than one thing at a time	0	0	0	0	0

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Collection: SELF_REPORT_TEEN_13_18_YR
Contains: S_TN_PHYSICAL, S_TN_EMOTIONAL, S_TN_SOCIAL, S_TN_COGNITIVE
Show if: (NOMAGE = TN)
```

	tion Block: S_ nins: S_TN_P3	
	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost	
	Always	

About My Health and Activities	Never	Almost Never	Sometimes	Often	Almost Always
It is hard for me to walk more than one $block S\_TN\_P3$	0	0	0	0	0
It is hard for me to run $S_TN_1$	P4 🔿	0	0	0	0
It is hard for me to do sports activity or exercise $\ S\_TN\_P5$	0	0	0	0	0
It is hard for me to lift something heavy $$S_TN_P6$$	0	0	0	0	0
It is hard for me to take a bath or shower by myself $\ensuremath{S\_TN}$	_p7 O	0	0	0	0
It is hard for me to do chores around the house $\underline{S_TN_P8}$	0	0	0	0	0
I hurt or ache <u>S_TN_P9</u>	0	0	0	0	0
I have low energy $S_TN_P10$	0	0	0	0	0

Page Break

	tion Block: S_ ains: S_TN_E12	
	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
· ·	Almost Always	

	About My Feelings	Never	Almost Never	Sometimes	Often	Almost Always
	I feel afraid or scared	0	0	0	0	0
S_TN_E13	I feel sad or blue	0	0	0	0	0
S_TN_E14		0	0	0	0	0
S_TN_E15	I have trouble sleeping	0	0	0	0	0
S_TN_E16	I worry about what will happen to me	0	0	0	0	0

Page Break

:	Scale Summa	ary
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
· ·	Almost Always	

Almost Almost How I Get Along with Others Never Never Sometimes Often Always I have trouble getting along  $S_TN_S18$ Ο 0  $\bigcirc$  $\bigcirc$ Ο with other teens Other teens do not want to be  $S_TN_S19$ Ο  $\bigcirc$ Ο  $\bigcirc$  $\bigcirc$ my friend  $S_TN_S20$ Other teens tease me  $\bigcirc$  $\bigcirc$  $\bigcirc$  $\bigcirc$  $\bigcirc$ I cannot do things that S\_TN\_S21 Ο Ο Ο Ο Ο other teens my age can do  $S_TN_S22$ It is hard to keep up with my  $\bigcirc$  $\bigcirc$  $\bigcirc$ Ο  $\bigcirc$ peers

uest	tion: S_TN_SC	27
	Scale Summa	
Code	Label	Show-If
	Never	
	Almost Never	
	Sometimes	
	Often	
	Almost Always	
	t is hard to Never	o pay a
C		lever
C	<sup>o</sup> Sometim	
	<sup>)</sup> Often	105
	Almost A	Alwavs
	/	
Quest	tion: S_TN_SC	28
	Scale Summa	iry
Code	Label	Show-If
0	Never	
1	Almost Never	
	Sometimes	
	Often	
4	Almost Always	
/ I	forget thi	ngs
	) Never	
C		
C	<sup>o</sup> Sometim	
	<sup>o</sup> Often	100
	<sup>D</sup> Almost A	lwavs
	/ 111050 /	aways
Quest	tion: S_TN_SC	29
	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
2	Sometimes	
	Often	
4	Almost Always	
ΛĪ	have trou	ble ke

I have trouble keeping up with my schoolwork
O Never S TN SC29

- O Almost Never
- O Sometimes
- Often

<sup>O</sup> Almost Always

Ouest	tion: S TN SC	30
2400	Scale Summa	
Code	Label	Show-If
0	Never	
1	Almost Never	
	Sometimes	
-	Often	
4	Almost Always	
	Almost N Sometim Often	lever ies
Quest	tion: S_TN_SC	
	Scale Summa	-
Code		Show-If
0	Never	
	Almost Never Sometimes	
	Often	
	Almost Always	
	Almost N Sometim Often	lever nes
	Annost P	always

	tion Block: S_	
	ains: S_TN_CF Scale Summa	
	Label	Show-If
		5110W-11
0	Never	
1	Almost Never	
2	Sometimes	
3	Often	
4	Almost	
	Always	

		Never	Almost Never	Sometimes	Often	Almost Always
S_TN_CF1	It is hard for me to keep my attention on things	0	0	0	0	0
S_TN_CF2	It is hard for me to remember what people tell me	0	0	0	0	0
S_TN_CF3	It is hard for me to remember what I just heard	0	0	0	0	0
S_TN_CF4	It is hard for me to think quickly	0	0	0	0	0
S_TN_CF5	I have trouble remembering what I was just thinking	0	0	0	0	0
S_TN_CF6	I have trouble remembering more than one thing at a time	0	0	0	0	0

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Variable Name PUDID	Label / Description Subject ID	Values / Formats
Timepoint	Time point	TIMEPOIN. 1 = Baseline 2 = Day 7 3 = Day 28 4 = 3 months 5 = 6 months 6 = 12 months
PARTICIPANT_STATUS	Subject participant status	STATUS. 1 = Home 2 = Home/Coma 3 = Inpatient 4 = Withdraw 5 = Subject not living 6 = No contact 7 = No follow-up
DATSTAT_PCTCOMPLETE	The survey language used by this participant. Number of questions answered by this participant. Number of questions presented to the participant. Number of questions unanswered by this participant. Percent complete. Percentage of questions unanswered by this participant.	
ONLINE_OR_PHONE	Would you prefer to do future surveys online, or by telephone interview?	SURVTYPE. 1 = Online (web-based survey) 2 = Telephone Interview
TOO_ILL CHILDCOMP	Is your child too ill to do the survey? Do you think your child will be able to answer questions in the child self-report sections?	1 = Yes, 0 = No 1 = Yes, 0 = No
CHILD_ASSENT	Is your child willing to answer questions about him/herself?	1 = Yes, 0 = No
PARENT_WILLING_STUDY	Are you willing to answer questions about your	
FAINT	child right now? Faintness or dizziness	1 = Yes, 0 = No LIKERT5B. 1 = Not At All 2 = A Little Bit 3 = Moderately 4 = Quite A Bit 5 = Extremely
CHEST_PAINS NAUSEA BREATH_TRBL NUMB WEAK NO_INTEREST LONELY BLUE WORTHLES HOPELES NERVOUS TENSE RESTLES SCARED PANIC FEARFUL UNPLANNED_VISIT_YN UNPLANNED_VISIT	Pains in heart or chest Nausea or upset stomach Trouble getting your breath Numbness or tingling in parts of your body Feeling weak in parts of your body Feeling mo interest in things Feeling lonely Feeling blue Feelings of worthlessness Feeling hopeless about the future Nervousness or shakiness inside Feeling tense or keyed up Feeling so restless you couldn't sit still Suddenly scared for no reason Spells of terror or panic Feeling fearful During the last 3 months, has your child had any unplanned visits to a doctor's office or clinic? How many unplanned visits were there during the last 3 months?	LIKERT5B LIKER

EmergRoomVisits	In the past 3 months, how many times did your child	
HospVisits	go to the emergency room? In the past 3 months, how many times did your child	
PLANNED_VISIT	spend one night or more in the hospital? How many planned follow-up visits did your child have	
CabaalDay	in the last 3 months?	VISITS
SchoolDay FA_WEACCPT	Does your child attend school or daycare? We feel accepted for what we are.	1 = Yes, 0 = No LIKERT4A.
FA_WEACCPT	we leel accepted for what we are.	
		1 = Strongly Agree 2 = Agree
		3 = Disagree
		4 = Strongly Disagree
FA SUPPORT	In times of crisis we can turn to each other for support.	LIKERT5A.
		0 = Never
		1 = Almost Never
		2 = Sometimes
		3 = Often
		4 = Almost Always
FA_PROB_SOLVE	We are able to make decisions about how to solve problems.	LIKERT4A
FA_CONFIDE	We confide in each other.	LIKERT4A
FA_EXPRES	We can express feelings to each other.	LIKERT4A
FA_ACCEPT	Individuals are accepted for what they are.	LIKERT4A
FA_AVOID	We avoid discussing our fears and concerns.	LIKERT4A
FA_BADFEEL	There are lots of bad feelings in the family.	LIKERT4A
FA_DECISN_PROB		LIKERT4A
FA_GETALNG_NO FA MISUNDER	We don't get along well together. Planning family activities is difficult because we misunderstand	LIKERT4A
FA_MISUNDER	each other	LIKERT4A
FA SADNES	We cannot talk to each other about the sadness we feel.	LIKERT4A
P_i0_PF4	Low energy level	LIKERT5A
P_i0_PF5	Difficulty participating in active play	LIKERT5A
P_i0_PF6	Having hurts or aches	LIKERT5A
P_i0_PF7	Feeling tired	LIKERT5A
P_i0_PF8	Being lethargic	LIKERT5A
P_i0_PF84	Resting a lot	LIKERT5A
P_i0_PS9	Having gas	LIKERT5A
P_i0_PS10	Spitting up after eating	LIKERT5A
P_i0_PS11	Difficulty breathing	LIKERT5A
P_i0_PS12	Being sick to his/her stomach	LIKERT5A
P_i0_PS13	Difficulty swallowing	LIKERT5A
P_i0_PS14 P_i0_PS15	Being constipated Having a rash	LIKERT5A LIKERT5A
P_i0_PS16	Having diarrhea	LIKERT5A
P_i0_PS17	Wheezing	LIKERT5A
P_i0_PS18	Vomiting	LIKERT5A
P_i0_E34	Feeling afraid or scared	LIKERT5A
P_i0_E35	Feeling angry	LIKERT5A
P_i0_E36	Crying or fussing when left alone	LIKERT5A
P_i0_E37	Difficulty soothing himself/herself when upset	LIKERT5A
P_i0_E38	Difficulty falling asleep	LIKERT5A
P_i0_E85	Crying or fussing while being cuddled	LIKERT5A
P_i0_E39	Feeling sad	LIKERT5A
P_i0_E40	Difficulty being soothed when picked up or held	LIKERT5A
P_i0_E41 P_i0_E42	Difficulty sleeping mostly through the night Crying a lot	LIKERT5A LIKERT5A
P_i0_E43	Feeling cranky	LIKERT5A
P_i0_E44	Difficulty taking naps during the day	LIKERT5A
P i0 S53	Not smiling at others	LIKERT5A
P_i0_S54	Not laughing when tickled	LIKERT5A
P_i0_S55	Not making eye contact with a caregiver	LIKERT5A
P_i0_S56	Not laughing when cuddled	LIKERT5A
P_i0_C66	Not imitating caregivers' actions	LIKERT5A
P_i0_C67	Not imitating caregivers' facial expressions	LIKERT5A
P_i0_C68	Not imitating caregivers' sounds	LIKERT5A
P_i0_C69	Not able to fix his/her attention on objects	LIKERT5A
P_i1_PF4	Low energy level	LIKERT5A
P_i1_PF5	Difficulty participating in active play	LIKERT5A
P_i1_PF6	Having hurts or aches	LIKERT5A

	Factors that	
P_i1_PF7	Feeling tired	LIKERT5A
P_i1_PF11	Being lethargic	LIKERT5A
P_i1_PF12	Resting a lot	LIKERT5A
P_i1_PF13	Feeling too tired to play	LIKERT5A
P_i1_PF14	Difficulty walking	LIKERT5A
P_i1_PF15	Difficulty running a short distance without falling	LIKERT5A
P_i1_E119	Crying or fussing while being cuddled	LIKERT5A
P_i1_E120	Difficulty taking naps during the day	LIKERT5A
P_i1_PS18	Having gas	LIKERT5A
P_i1_PS21	Being sick to his/her stomach	LIKERT5A
P_i1_PS22	Difficulty swallowing	LIKERT5A
P_i1_PS25	Being constipated	LIKERT5A
P_i1_PS26	Having a rash	LIKERT5A
P_i1_PS27	Having diarrhea	LIKERT5A
P_i1_PS28	Wheezing	LIKERT5A
P_i1_PS29	Vomiting	LIKERT5A
P_i1_E49	Feeling afraid or scared	LIKERT5A
P_i1_E50	Feeling angry	LIKERT5A
P_i1_E51	Crying or fussing when left alone	LIKERT5A
P_i1_E52	Difficulty soothing himself/herself when upset	LIKERT5A
P_i1_E53	Difficulty falling asleep	LIKERT5A
P_i1_E54	Feeling sad	LIKERT5A
P_i1_E55	Difficulty being soothed when picked up or held	LIKERT5A
P_i1_E56	Difficulty sleeping mostly through the night	LIKERT5A
P_i1_E57	Crying a lot	LIKERT5A
P_i1_E58	Feeling cranky	LIKERT5A
P_i1_PS19	Spitting up after eating	LIKERT5A
P_i1_PS20	Difficulty breathing	LIKERT5A
P_i1_S68	Not smiling at others	LIKERT5A
P_i1_S70	Being uncomfortable around other children	LIKERT5A
P_i1_S71	Not laughing when tickled	LIKERT5A
P_i1_S72	Not making eye contact with a caregiver	LIKERT5A
P_i1_S73	Not laughing when cuddled	LIKERT5A
P_i1_C88	Not imitating caregivers' actions	LIKERT5A
P_i1_C89	Not imitating caregivers' facial expressions	LIKERT5A
P_i1_C90	Not able to fix his/her attention on objects	LIKERT5A
P_i1_C95	Difficulty naming familiar objects	LIKERT5A
P_i1_C96	Difficulty pointing to his/her body parts when asked	LIKERT5A
P_i1_C97	Difficulty repeating words	LIKERT5A
P_i1_C98	Difficulty keeping his/her attention on things	LIKERT5A
P_i1_C121	Not imitating caregivers' sounds	LIKERT5A
P_i1_C122	Not imitating caregivers' speech	LIKERT5A
P_T_P3	Walking	LIKERT5A
P_T_P4	Running	LIKERT5A
P_T_P5	Participating in active play or exercise	LIKERT5A
P_T_P6	Lifting something heavy	LIKERT5A
P_T_P7	Bathing	LIKERT5A
P_T_P8	Helping to pick up his or her toys	LIKERT5A
P_T_P9	Having hurts or aches	LIKERT5A
P_T_P10	Low energy level	LIKERT5A
P_T_E12	Feeling afraid or scared	LIKERT5A
P_T_E13	Feeling sad or blue	LIKERT5A
P_T_E14	Feeling angry	LIKERT5A
P_T_E15	Trouble sleeping	LIKERT5A
P_T_E16	Worrying	LIKERT5A
P_T_S18	Playing with other children	LIKERT5A
P_T_S19	Other kids not wanting to play with him or her	LIKERT5A
P_T_S20	Getting teased by other children	LIKERT5A
P_T_S21	Not able to do things that other children his or her age can do	LIKERT5A
P_T_S22	Keeping up when playing with other children	LIKERT5A
P_T_SD24	Doing the same school/daycare activities as peers	LIKERT5A
P_T_SD25	Missing school/daycare because of not feeling well	LIKERT5A
P_T_SD26	Missing school/daycare to go to the doctor or hospital	LIKERT5A
P_T_CF1	Difficulty keeping his/her attention on things	LIKERT5A
P_T_CF2	Difficulty remembering what people tell him/her	LIKERT5A
P_T_CF3	Difficulty remembering what he/she just heard	LIKERT5A
P_T_CF4	Difficulty thinking quickly	LIKERT5A
P_T_CF5	Trouble remembering what he/she was just thinking	LIKERT5A

P_T_CF6	Trouble remembering more than one thing at a time	LIKERT5A
P_YC_P3	Walking more than one block	LIKERT5A
P_YC_P4	Running	LIKERT5A
P_YC_P5	Participating in sports activity or exercise	LIKERT5A
P_YC_P6	Lifting something heavy	LIKERT5A
P_YC_P7	Taking a bath or shower by him or herself	LIKERT5A
P YC P8	Doing chores, like picking up his or her toys	LIKERT5A
P_YC_P9	Having hurts or aches	LIKERT5A
P_YC_P10	Low energy level	LIKERT5A
P_YC_E12	Feeling afraid or scared	LIKERT5A
P_YC_E13	Feeling sad or blue	LIKERT5A
P_YC_E14	Feeling angry	LIKERT5A
P_YC_E15	Trouble sleeping	LIKERT5A
P_YC_E16	Worrying about what will happen to him or her	LIKERT5A
P_YC_S18	Getting along with other children	LIKERT5A
P_YC_S19	Other kids not wanting to be his or her friend	LIKERT5A
P_YC_S20	Getting teased by other children	LIKERT5A
P_YC_S21	Not able to do things that other children his or her age can do	LIKERT5A
P_YC_S22	Keeping up when playing with other children	LIKERT5A
P_YC_SC27	Paying attention in class	LIKERT5A
P_YC_SC28	Forgetting things	LIKERT5A
P_YC_SC29	Keeping up with school activities	LIKERT5A
P_YC_SC30	Missing school because of not feeling well	LIKERT5A
P_YC_SC31	Missing school to go to the doctor or hospital	LIKERT5A
P_YC_CF1	Difficulty keeping his/her attention on things	LIKERT5A
P_YC_CF2	Difficulty remembering what people tell him/her	LIKERT5A
P_YC_CF3	Difficulty remembering what he/she just heard	LIKERT5A
P_YC_CF4	Difficulty thinking quickly	LIKERT5A
P_YC_CF5	Trouble remembering what he/she was just thinking	LIKERT5A
P_YC_CF6	Trouble remembering more than one thing at a time	LIKERT5A
P_C_P3	Walking more than one block	LIKERT5A
P_C_P4	Running	LIKERT5A
P_C_P5	Participating in sports activity or exercise	LIKERT5A
P_C_P6	Lifting something heavy	LIKERT5A
P_C_P7	Taking a bath or shower by him or herself	LIKERT5A
P_C_P8	Doing chores around the house	LIKERT5A
P_C_P9	Having hurts or aches	LIKERT5A
P_C_P10	Low energy level	LIKERT5A
S_C_P3	It is hard for me to walk more than one block	LIKERT5A
S_C_P4	It is hard for me to run	LIKERT5A
S_C_P5	It is hard for me to do sports activity or exercise	LIKERT5A
S C P6	It is hard for me to lift something heavy	LIKERT5A
S_C_P7	It is hard for me to take a bath or shower by myself	LIKERT5A
S_C_P8	It is hard for me to do chores around the house	LIKERT5A
S_C_P9	I hurt or ache	LIKERT5A
S_C_P10	I have low energy	LIKERT5A
P_C_E12	Feeling afraid or scared	LIKERT5A
P_C_E13	Feeling sad or blue	LIKERT5A
P_C_E14	Feeling angry	LIKERT5A
P_C_E15	Trouble sleeping	LIKERT5A
P_C_E16	Worrying about what will happen to him or her	LIKERT5A
S_C_E12	I feel afraid or scared	LIKERT5A
S_C_E13	I feel sad or blue	LIKERT5A
S_C_E14	I feel angry	LIKERT5A
S_C_E15	I have trouble sleeping	LIKERT5A
S_C_E16	I worry about what will happen to me	LIKERT5A
P_C_S18		LIKERT5A
	Getting along with other children	
P_C_S19	Other kids not wanting to be his or her friend	LIKERT5A
P_C_S20	Getting teased by other children	LIKERT5A
P_C_S21	Not able to do things that other children his or her age can do	LIKERT5A
P_C_S22	Keeping up when playing with other children	LIKERT5A
S_C_S18	I have trouble getting along with other kids	LIKERT5A
S_C_S19	Other kids do not want to be my friend	LIKERT5A
S_C_S20	Other kids tease me	LIKERT5A
S_C_S21	I cannot do things that other kids my age can do	LIKERT5A
S_C_S22	It is hard to keep up when I play with other kids	LIKERT5A
P_C_SC27	Paying attention in class	LIKERT5A
P_C_SC28	Forgetting things	LIKERT5A

P_C_SC29	Keeping up with school activities	LIKERT5A
P_C_SC30	Missing school because of not feeling well	LIKERT5A
P_C_SC31	Missing school to go to the doctor or hospital	LIKERT5A
S_C_SC27	It is hard to pay attention in class	LIKERT5A
S_C_SC28	I forget things	LIKERT5A
S_C_SC29	I have trouble keeping up with my schoolwork	LIKERT5A
S_C_SC30	I miss school because of not feeling well	LIKERT5A
S_C_SC31	I miss school to go to the doctor or hospital	LIKERT5A
P_C_CF1	Difficulty keeping his/her attention on things	LIKERT5A
P C CF2	Difficulty remembering what people tell him/her	LIKERT5A
P_C_CF3	Difficulty remembering what he/she just heard	LIKERT5A
P_C_CF4	Difficulty thinking quickly	LIKERT5A
P_C_CF5	Trouble remembering what he/she was just thinking	LIKERT5A
P_C_CF6		LIKERT5A
	Trouble remembering more than one thing at a time	
S_C_CF1	It is hard for me to keep my attention on things	LIKERT5A
S_C_CF2	It is hard for me to remember what people tell me	LIKERT5A
S_C_CF3	It is hard for me to remember what I just heard	LIKERT5A
S_C_CF4	It is hard for me to think quickly	LIKERT5A
S_C_CF5	I have trouble remembering what I was just thinking	LIKERT5A
S_C_CF6	I have trouble remembering more than one thing at a time	LIKERT5A
P_TN_P3	Walking more than one block	LIKERT5A
P_TN_P4	Running	LIKERT5A
P_TN_P5	Participating in sports activity or exercise	LIKERT5A
P_TN_P6	Lifting something heavy	LIKERT5A
P_TN_P7	Taking a bath or shower by him or herself	LIKERT5A
P_TN_P8	Doing chores around the house	LIKERT5A
P_TN_P9	Having hurts or aches	LIKERT5A
P_TN_P10	Low energy level	LIKERT5A
S_TN_P3	It is hard for me to walk more than one block	LIKERT5A
S_TN_P4	It is hard for me to run	LIKERT5A
S_TN_P5	It is hard for me to do sports activity or exercise	LIKERT5A
S_TN_P6	It is hard for me to lift something heavy	LIKERT5A
S_TN_P7	It is hard for me to take a bath or shower by myself	LIKERT5A
	It is hard for me to do chores around the house	
S_TN_P8		LIKERT5A
S_TN_P9	I hurt or ache	LIKERT5A
S_TN_P10	I have low energy	LIKERT5A
P_TN_E12	Feeling afraid or scared	LIKERT5A
P_TN_E13	Feeling sad or blue	LIKERT5A
P_TN_E14	Feeling angry	LIKERT5A
P_TN_E15	Trouble sleeping	LIKERT5A
P_TN_E16	Worrying about what will happen to him or her	LIKERT5A
S_TN_E12	I feel afraid or scared	LIKERT5A
S_TN_E13	I feel sad or blue	LIKERT5A
S_TN_E14	I feel angry	LIKERT5A
S_TN_E15	I have trouble sleeping	LIKERT5A
S_TN_E16	I worry about what will happen to me	LIKERT5A
P_TN_S18	Getting along with other teens	LIKERT5A
P_TN_S19	Other teens not wanting to be his or her friend	LIKERT5A
P TN S20	Getting teased by other teens	LIKERT5A
P_TN_S21	Not able to do things that other teens his or her age can do	LIKERT5A
P_TN_S22	Keeping up with other teens	LIKERT5A
S TN S18	I have trouble getting along with other teens	LIKERT5A
S_TN_S19	Other teens do not want to be my friend	LIKERT5A
S_TN_S20	Other teens tease me	LIKERT5A
S_TN_S21	I cannot do things that other teens my age can do	LIKERT5A
S_TN_S22	It is hard to keep up with my peers	LIKERT5A
P_TN_SC27	Paying attention in class	LIKERT5A
P_TN_SC28	Forgetting things	LIKERT5A
P_TN_SC29	Keeping up with school activities	LIKERT5A
P_TN_SC30	Missing school because of not feeling well	LIKERT5A
P_TN_SC31	Missing school to go to the doctor or hospital	LIKERT5A
S_TN_SC27	It is hard to pay attention in class	LIKERT5A
S_TN_SC28	I forget things	LIKERT5A
S_TN_SC29	I have trouble keeping up with my schoolwork	LIKERT5A
S_TN_SC30	I miss school because of not feeling well	LIKERT5A
S_TN_SC31	I miss school to go to the doctor or hospital	LIKERT5A
P_TN_CF1	Difficulty keeping his/her attention on things	LIKERT5A
P_TN_CF2	Difficulty remembering what people tell him/her	LIKERT5A
P_TN_CF3	Difficulty remembering what he/she just heard	LIKERT5A
P_TN_CF4	Difficulty thinking quickly	LIKERT5A
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P_TN_CF5	Trouble remembering what he/she was just thinking	LIKERT5A
P_TN_CF6	Trouble remembering more than one thing at a time	LIKERT5A
S_TN_CF1	It is hard for me to keep my attention on things	LIKERT5A
S_TN_CF2	It is hard for me to remember what people tell me	LIKERT5A
S_TN_CF3	It is hard for me to remember what I just heard	LIKERT5A
S_TN_CF4	It is hard for me to think quickly	LIKERT5A
S_TN_CF5	I have trouble remembering what I was just thinking	LIKERT5A
S_TN_CF6	I have trouble remembering more than one thing at a time	LIKERT5A
COMMUNICATE	Did he/she communicate what he/she wanted?	LIKERT3A.
		0 = Never or rarely
		1 = Some of the time
		2 = Almost always
CONTENT	Did he/she seem contented and cheerful?	LIKERT3A
CROSS	Did he/she seem unusually irritable and cross?	LIKERT3A
CRYING	Did he/she react to little things by crying?	LIKERT3A
DIFFICULT	Did he/she seem unusually difficult?	LIKERT3A
EATWELL	Did he/she eat well?	LIKERT3A
INTEREST	Did he/she seem interested in what was going on around him/her?	LIKERT3A
LIVELY	Did he/she seem lively and energetic?	LIKERT3A
MOODY	Did he/she act moody?	LIKERT3A
OCCUPY	Did he/she occupy him/herself?	LIKERT3A
RESPOND	Did he/she respond to your attention?	LIKERT3A
SICK	Did he/she seem to feel sick and tired?	LIKERT3A
SLEEPNIGHT	Did he/she sleep through the night?	LIKERT3A
SLEEPWELL	Did he/she sleep well?	LIKERT3A