

Collaborative Pediatric Critical Care Research Network ARDS Study Overview of Public Use Datasets

This document provides an overview of the general principles used in creating the public use datasets for the *Eunice Kennedy Shriver* National Institute for Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN) ARDS Study. There are 25 data sets available as both CSV and SAS® (.SAS7BDAT) files (with formats and labels). Accompanying documentation and resources provided include the study protocol, data dictionary (codebook), and for each dataset an HTML document summarizing variables in the associated dataset (i.e., frequency distributions or descriptive statistics). Documents detailing data entry instructions and responses to frequently asked questions are also included (Manual of Operations (MOO) and FAQ). For SAS software users, an example script to set up the SAS library and apply SAS formats is provided. The codebook should be referenced frequently during analysis, as this is the most complete reference of all variables included in each dataset.

GENERAL PRINCIPLES FOR CREATION OF DATASETS

- The population for the public use dataset is all enrolled subjects, i.e. eligible subjects with guardian consent.
- Open text fields and other variables have been reviewed for sensitive or identifying information and modified as needed.
- All date variables are recoded to be number of days since date of screening (ScreenDate). ‘Date’ in variable names and labels are changed to ‘Day’ throughout. For example, the variable HospDisDate will be called HOSPDISDAY and the label will change from “Hospital discharge date” to “Hospital discharge day (relative to screening date)”. No actual dates are included.
- Within each dataset, the PUDID is a masked identifier.

LIST OF PUBLIC USE DATASETS AVAILABLE

- 1 (BASELINEPRISM) PRISM Score form
- 2 (CHESTXRAYLOG_DAILYXRAY) Chest x-ray results log
- 3 (DAILYARDSDATA) ARDS study data collected daily up to ICU discharge or Day 28, whichever occurs first
- 4 (DAILYARDSDATA_DAILYINHALE) Inhaled medications log on study
- 5 (DAYODATA) ARDS study data collected on Day 0, calendar day subject met study inclusion criteria
- 6 (DAYODATA_DAYOINHALE) Inhaled medications log on Day 0
- 7 (DEMOGRAPHICS) Demographics information
- 8 (DIAGNOSIS) ICU diagnoses and ARDS risk factors
- 9 (ELIGIBILITY) Study eligibility information
- 10 (ELIGIBILITYPRISM) PRISM score at eligibility
- 11 (ENROLLEDSUBJECTS) Primary subject-level dataset containing clinical and follow-up data

- 12 (HOSPSUMMARY) Hospital summary information including hospital and ICU length-of-stay
- 13 (INFANTPEDSQL) Raw PEDSQL survey responses at Baseline and ICU Discharge/Day 28/Death
- 14 (MICROBIOLOGY) Microbiology results on study YN
- 15 (MICROBIOLOGY_MICROBIOLOGY) Microbiology results on study log
- 16 (MICROBIOLOGY_MICROORGANISM) Microbiology results, upload abstractions
- 17 (PCPC) PCPC Score
- 18 (PEDSQLCHILD) Child PEDSQL survey responses at Baseline and ICU Discharge/Day 28/Death for non-infant study participants.
- 19 (PEDSQLPARENT) Parent PEDSQL survey responses at Baseline and ICU Discharge/Day 28/Death for non-infant study participants.
- 20 (PELOD) PELOD-II Score
- 21 (SAMPLEDAY1) ARDS study sample collection and handling data on Day 1
- 22 (SAMPLEDAY3) ARDS study sample collection and handling data on Day 3
- 23 (VENTILATIONLOG) Mechanical ventilation YN
- 24 (VENTILATIONLOG_DAILYVENTILATION) Mechanical ventilation log
- 25 (WOC) Withdrawal of consent