

Collaborative Pediatric Critical Care Research Network Bereavement 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) Bereavement Study. There are a total of 8 datasets available as both CSV and SAS® (.SAS7BDAT) files (with formats and labels). Accompanying documentation and resources provided include the study protocol, the annotated CRF, and, for each dataset, a PDF document summarizing variables in the associated dataset (i.e., frequency distributions or descriptive statistics). For SAS software users, an example script to set up the SAS library and apply SAS formats is also provided. The annotated CRF should be referenced frequently during analysis as this is the most complete reference of all variables included in each dataset. Please see the attached Research Data Use Agreement (RDUA) for a description of intended use and disclaimer.

GENERAL PRINCIPLES FOR CREATION OF DATASET

1. The population for the public use dataset is all parents who completed some or all of the survey materials at 6 months. See the protocol for a detailed list of inclusion/exclusion criteria and for additional details of study conduct.
2. The datasets are primarily based on raw data as collected by the clinical sites. In addition, we have included survey scoring instructions and a dataset with calculated survey scores. All variables are described in the annotated CRF.
3. Open text fields and other variables have been reviewed for sensitive or identifying information and modified as needed. Dates were recoded to reflect relevant time intervals.
4. Within each dataset, the SubjectID represents a deceased child, or participating family. Please note, however, that this is not the unique identifier within a dataset. Multiple records could have this SubjectID if more than one parent participated or a parent participated at both 6 and 18 months. The annotated CRF provides information as to the structure of each dataset and the unique identifier for each record.

LIST OF PUBLIC USE DATASETS AVAILABLE

- Relationship Scales Questionnaire (RSQ)
- Inventory of Complicated Grief (ICG)
- Grief Related Avoidance Questionnaire (GRIEFAVOID)
- Caregiving Questionnaire (CAREGIVING)
- Social Support Questionnaire (SUPPORT)
- Social Support Questionnaire - Contacts (SUPPORTCONTACTS)
- Parent and Child Information (PARENT)
- Survey Scores at 6 and 18 months (SURVEYSCORES)