



United States

Network of PEDIATRIC MULTIPLE SCLEROSIS Centers

Public Use Datasets

Data from NPMSC, including the Pediatric Multiple Sclerosis and other Demyelinating Diseases (PeMSDD) database, constitute an important scientific resource. To enhance the public health benefit of these studies, public use datasets will be made available to qualified researchers.

NPMSC datasets will be provided only to investigators who agree to adhere to the signed research data use agreement. Dataset creation and distribution will be performed by the data coordinating center.

Definitions:

- **Public Use Dataset** – De-identified dataset derived from completed Pediatric Multiple Sclerosis and other Demyelinating Diseases (PeMSDD) database.
- **Research Data Use Agreement** – Agreement between the recipient institution, investigator and the data coordinating center, governing the use of the specific dataset.

Procedures:

The data coordinating center will provide the data set, electronic copies of the data worksheets, the final study protocol and a data dictionary. No further support will be provided by the data coordinating center, network investigators to the recipient investigator. Investigators will request the use of the dataset by submitting a formal request in the form of a brief research plan describing the proposed research.

Investigators will request the use of a specific dataset by submitting a formal request that includes:

- A research plan describing the proposed research,
- A signed data Research Data Use Agreement (RDUa)

The data coordinating center will disseminate the dataset after receipt of the aforementioned items.

Contact: For further information contact Melissa Bolton, MBA, CCRC, NPMSC Data Coordinating Center Program Lead at melissa.bolton@hsc.utah.edu

Available Study Datasets from NPMSC Research Projects:

- Pediatric Multiple Sclerosis and other Demyelinating Diseases Database (PeMSDD)
 - **Study Type:** Registry
 - **Study Period:** 2010 – Ongoing
 - **Enrollment:** 3,000+

- **Purpose:** This study, funded by the National MS Society includes patients with suspected onset of demyelinating disease of the central nervous system (CNS) prior to age 18. The purposes of the database are to describe the number and characteristics of patients with suspected early onset of demyelinating disease and to support hypothesis generation and study design development for clinical trials and observational studies to be carried out by the NPMSC. Patient data include demographics and longitudinal developmental and clinical data.