

## CureSCi CDE Project Sleep Subgroup Summary

The goals of the CureSCi CDE project are to support the NIH roadmap and address challenges of varied data collection standards and difficulties in comparing between studies and poor definitions around the specific data elements collected. CDEs are recommended by the NIH Strategic Plan for Data Science improving data quality, facilitating collection of data, data-sharing and comparison and reducing study start-up time and overall study cost.

In regards to sleep data, the group believes the best approach to take with sleep data as well as sleep questionnaires is to have investigators use National Sleep Research Resource (<https://sleepdata.org/>), a platform specifically designed by NHLBI for this purpose. This website is a link to a platform for investigators to upload raw sleep study data, manuals of procedures, questionnaires, case report forms and data dictionaries with definitions and code when available. The site is freely available. The group encourages investigators to review the platform including viewing datasets of data from other clinical trials and research programs.

There are analysts available who can score, classify, and analyze the uploaded raw data using whatever definitions and parameters are set up by the investigator. Therefore, if national guidelines change on how sleep apnea is defined for example, raw data can be re-analyzed.

There are several existing datasets from 20-30 multi center sleep trials that investigators can apply to have access to. This provides opportunity for control subjects, since several of the datasets have large numbers of African American subjects from the general population. Others might even include a small number of patients with sickle cell disease.

**Sleep Data - National Sleep Research Resource – NSRR** - National Research Resource offers free web access to large collections of de-identified physiological signals and clinical data elements collected in well-characterized research cohorts and clinical trials. The initial data resource is from the Sleep Heart Health Study.

Sleep questionnaires were included from PROMIS and ASCQ-ME along with forms from previous studies as examples that may be used in studies collecting sleep data. All these forms are Supplemental.

- [Sleep Apnea in Children](https://www.phenxtoolkit.org/protocols/view/91501) (https://www.phenxtoolkit.org/protocols/view/91501)
- [ASCQ-ME Sleep Impact \(long and short\)](https://www.phenxtoolkit.org/protocols/view/820201) (https://www.phenxtoolkit.org/protocols/view/820201)
- [PROMIS Sleep Disturbance](https://www.healthmeasures.net/) (https://www.healthmeasures.net/)
- [PROMIS Sleep-Related Impairment](https://www.healthmeasures.net/) (https://www.healthmeasures.net/)
- [Sleep Questionnaire - Child](https://curesicklecell.rti.org/Forms/SAC-II_Sleep.pdf) (https://curesicklecell.rti.org/Forms/SAC-II\_Sleep.pdf)