

**NINDS CDE Project
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
Baseline/Covariate Information Subgroup**

The Baseline/Covariate Information Subgroup reviewed data collection instruments widely used by investigators in the field, and either recommended their use unchanged or (more often) proposed some modifications. The instruments recommended by the Subgroup apply only to adult patients. There were no pediatricians in our Subgroup.

The Subgroup believe that ME/CFS has a “fuzzy phenotype”: without a biomarker “gold standard” for diagnosis, it is hard to “validate” any instrument. The work of the Baseline/Covariate Subgroup focused entirely on adults with ME/CFS. Areas for further research and development would revolve around similar instruments needing to be created/adapted for children/teens. Note: The DSQ-Pediatric Screening Questionnaire (DSQ-PSQ) was added by pediatric specialist from within other ME/CFS CDE subgroups.

Below is a table overview of the Instruments and Case Report Form (CRF) recommended by the Subgroup:

Recommendations Summary Table

Instrument/CRF Name	Population	Classification
General Core	Adult	Core
Past and Current Illnesses	Adult	Core
DePaul Symptom Questionnaire (DSQ)	Adult	Core Option
ME/CFS Symptom Checklist	Adult	Core Option
Family Health History	Adult	Supplemental - Highly Recommended
Medications/Other Treatments	Adult	Supplemental - Highly Recommended
Adult Employment and Education History	Adult	Supplemental - Highly Recommended
Physical Examination Form	Adult	Supplemental - Highly Recommended
Demographics	Adult	Supplemental
Laboratory Test Results	Adult	Supplemental
Modifiable Activity Questionnaire (MAQ)	Adult	Supplemental
DSQ-Pediatric Screening Questionnaire (DSQ-PSQ)	Pediatric	Supplemental