



## Summary of Core/Supplemental – Highly Recommended Recommendations: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs

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### Start-up Resource – NINDS ME/CFS CDE Recommendations

Each CDE or instrument could be classified according to the definitions below:

**General Core:** A data element that is required for all NINDS funded studies.

**Disease Core:** A data element that collects essential information applicable to any disease-specific study, including all therapeutic areas. The NINDS and its appointed working groups assign the disease “Core” classification based on the current clinical research best practices. In each case, the disease Core CDEs are a small subset of the available CDEs, where it is anticipated that investigators will need to collect the disease Core CDEs on any type of study. These are required for all disease-specific studies.

**Disease Supplemental - Highly Recommended:** A data element which is essential based on certain conditions or study types in clinical research studies. In most cases, these have been used and validated in the disease area. These data elements are strongly recommended for the specified disease condition, study type or design.

**Disease Supplemental:** A data element which is commonly collected in clinical research studies. Use depends upon the study design, protocol or type of research involved.

**Disease Exploratory:** A data element that requires further validation but may fill current gaps in the CDEs and/or substitute for an existing CDE once validation is complete. Such data elements show great promise but require further validation before they are ready for prime-time use in clinical research studies. They are reasonable to use with the understanding that it has limited validation in the target group.



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<p><b>NIH Resources:</b> <i>The NINDS also strongly encourages researchers to use these NIH developed materials for NINDS-sponsored research, when appropriate. Utilization of these resources will enable greater consistency for NINDS-sponsored research studies. Some of these tools are free of charge.</i></p>	<p><b>NIH Toolbox</b>  <b>Patient-Reported Outcomes Measurement Information System (PROMIS)</b>  <b>Quality of Life in Neurological Disorders (Neuro-QOL)</b></p>
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### Core CDEs for all NINDS Studies<sup>1</sup>:

Domain/Sub-Domain	CDE Name	CDE ID	Study Type
Participant Characteristics; Demographics	Birth date	C00007	All studies
Participant Characteristics; Demographics	Ethnicity USA category	C00020	All studies
Participant Characteristics; Demographics	Race USA category	C00030	All studies
Participant Characteristics; Demographics	Birth sex assigned type	C58676	All studies
Participant Characteristics; Demographics	Gender identity type	C58677	All studies
Participant History and Family History; General Health History	Medical history condition text	C00322	All studies
Participant History and Family History; General Health History	Medical history condition SNOMED CT code	C00313	All studies

### Core CDEs for ME/CFS Studies:

Domain; Sub-Domain	Core Data element	CDE ID
Participant Characteristics; Demographics	Marital or partner status	C00207

<sup>1</sup> Note: Education year count C00015 is no longer a general Core CDE

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Domain; Sub-Domain	Core Data element	CDE ID
Participant History and Family History; General Health History	Condition illness indicator	C58171
Participant History and Family History; General Health History	Condition illness indicator age onset value	C58172
Participant History and Family History; General Health History	Condition illness indicator still present text	C58173
Participant History and Family History; General Health History	Past current blood disorders illness type	C58238
Participant History and Family History; General Health History	Other bleeding disorder text	C58278
Participant History and Family History; General Health History	Blood clot disorder text	C58282
Participant History and Family History; General Health History	Other blood disorder text	C58284
Participant History and Family History; General Health History	Past current cardiovascular illness type	C58239
Participant History and Family History; General Health History	Past current cardiovascular heart disease type text	C58271
Participant History and Family History; General Health History	Past current cardiovascular cholesterol type text	C58275
Participant History and Family History; General Health History	Heart rhythm problem text	C58287
Participant History and Family History; General Health History	Other cardiovascular condition text	C58288
Participant History and Family History; General Health History	Past current chest illness type	C58297



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Domain; Sub-Domain	Core Data element	CDE ID
Participant History and Family History; General Health History	Pneumonia type text	C58301
Participant History and Family History; General Health History	Other chronic lung condition text	C58302
Participant History and Family History; General Health History	Past current ear nose throat condition type	C58314
Participant History and Family History; General Health History	Past current eye condition type	C58316
Participant History and Family History; General Health History	Other eye condition text	C58318
Participant History and Family History; General Health History	Past current endocrine metabolic illness type	C58317
Participant History and Family History; General Health History	Past current gastrointestinal illness type	C58319
Participant History and Family History; General Health History	Other liver disease text	C58320
Participant History and Family History; General Health History	Past current neurological illness type	C58321
Participant History and Family History; General Health History	Alzheimer dementia type text	C58328
Participant History and Family History; General Health History	Other sleep disorder type text	C58351
Participant History and Family History; General Health History	Neuromuscular disorder type text	C58329
Participant History and Family History; General Health History	Muscle disease text	C58330



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Domain; Sub-Domain	Core Data element	CDE ID
Participant History and Family History; General Health History	Past current rheumatological illness type	C58325
Participant History and Family History; General Health History	Other autoimmune disease text	C58331
Participant History and Family History; General Health History	Past current psychological illness type	C58341
Participant History and Family History; General Health History	Other psychosis type text	C58352
Participant History and Family History; General Health History	Past current skin problems type	C58343
Participant History and Family History; General Health History	Other skin problems type text	C58353
Participant History and Family History; General Health History	Past current tumors cancer illness type	C58344
Participant History and Family History; General Health History	Other cancer type text	C58354
Participant History and Family History; General Health History	Past current urological condition type	C58346
Participant History and Family History; General Health History	Other sexually transmitted diseases type text	C58355
Participant History and Family History; General Health History	Other kidney problem type text	C58356
Participant History and Family History; General Health History	Past current female only condition type	C58347
Participant History and Family History; General Health History	Gravida maternal value	C11065



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Domain; Sub-Domain	Core Data element	CDE ID
Participant History and Family History; General Health History	Parity maternal value	C11063
Participant History and Family History; General Health History	Pregnancy medical terminations count	C14151
Participant History and Family History; General Health History	Spontaneous miscarriage count	C10559
Participant History and Family History; General Health History	Other genital infections type text	C58357
Participant History and Family History; General Health History	Other gynecological condition type text	C58359
Participant History and Family History; General Health History	Past current male only condition type	C58348
Participant History and Family History; General Health History	Other male problems type text	C58361
Participant History and Family History; General Health History	Past current miscellaneous illness type	C58350
Participant History and Family History; General Health History	Immune deficiency type text	C58363
Participant History and Family History; General Health History	Organ type text	C58365
Participant History and Family History; General Health History	Past surgery type	C58368
Participant History and Family History; General Health History	Past surgery type indicator	C58370
Participant History and Family History; General Health History	Past surgery performed institution name	C58372

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Domain; Sub-Domain	Core Data element	CDE ID
Participant History and Family History; General Health History	Past surgery performed city name	C58373
Participant History and Family History; General Health History	Surgery performed date	C19096
Participant History and Family History; General Health History	Other surgeries performed text	C58374
Participant History and Family History; General Health History	Immune symptom onset type	C57261
Assessments and Examinations; Post-Exertional Malaise	Site name	C17402
Assessments and Examinations; Post-Exertional Malaise	Subject ID	C19247
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) <sup>2</sup> - Dead heavy feeling after exercise frequency scale	C57091
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Dead heavy feeling after exercise severity scale	C57092
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Soreness next day frequency scale	C57093
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Soreness next day severity scale	C57094

<sup>2</sup> Note that entire DePaul Symptom Questionnaire is Core Option (listed below) and that these are specifically for PEM in all studies.

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Domain; Sub-Domain	Core Data element	CDE ID
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Mentally tired after slight effort frequency scale	C57095
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Mentally tired after slight effort severity scale	C57096
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Minimum exercise make physical tired frequency scale	C57097
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Minimum exercise physical tired severity scale	C57098
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Physical drain after mild activity frequency scale	C57099
Assessments and Examinations; Post-Exertional Malaise	DePaul Symptom Questionnaire (DSQ) - Physical drain after mild activity severity scale	C57100
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise DePaul Symptom Questionnaire threshold met indicator	C57069
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise diagnosis method type	C57070
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise experience indicator	C57071



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Domain; Sub-Domain	Core Data element	CDE ID
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Thyroid-Stimulating hormone test result value	C57156
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Thyroid-Stimulating hormone test result unit of measure	C57157
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Thyroid-Stimulating hormone test date and time	C57158
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Subject ID	C19247
Outcomes and End Points; Sleep	Site name	C17402
Outcomes and End Points; Sleep	Subject ID	C19247
Outcomes and End Points; Sleep	Sleep issue treatment indicator	C57072
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) <sup>3</sup> - Feeling unrefresh after wake-up frequency scale	C57079
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Feel unrefresh after wake-up severity scale	C57080

<sup>3</sup> Note that entire DePaul Symptom Questionnaire is Core Option (listed below) and that these are specifically for sleep in all studies.

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Domain; Sub-Domain	Core Data element	CDE ID
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Need nap daily frequency scale	C57081
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Need nap daily severity scale	C57082
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Problem fall asleep frequency scale	C57083
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Problem fall asleep severity scale	C57084
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Problem stay asleep frequency scale	C57085
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Problem stay asleep severity scale	C57086
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) – Wake-up early frequency scale	C57087
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) – Wake-up early severity scale	C57088
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Sleep during day awake night frequency scale	C57089



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Domain; Sub-Domain	Core Data element	CDE ID
Outcomes and End Points; Sleep	DePaul Symptom Questionnaire (DSQ) - Sleep during day awake night severity scale	C57090

**Supplemental – Highly Recommended CDEs for ME/CFS Studies:**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Participant Characteristics; Demographics	Education year count	C00015
Participant History and Family History; General Health History	ROME I criteria type	C57358
Participant History and Family History; General Health History	ROME II criteria type	C57363
Participant History and Family History; General Health History	Study protocol name	C19256
Participant History and Family History; General Health History	Site name	C17402
Participant History and Family History; General Health History	Subject ID	C19247
Participant History and Family History; General Health History	Family health problems history relative type	C58086
Participant History and Family History; General Health History	Comment text	C18027
Participant History and Family History; General Health History	Family health problems blood disorders history type	C58087

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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Participant History and Family History; General Health History	Blood disorders anemia type text	C58088
Participant History and Family History; General Health History	Blood disorders bleeding disorder type text	C58105
Participant History and Family History; General Health History	Family health problems cardiovascular history type	C58089
Participant History and Family History; General Health History	Cardiovascular low blood pressure type text	C58090
Participant History and Family History; General Health History	Cardiovascular cholesterol type text	C58106
Participant History and Family History; General Health History	Cardiovascular heart disease type text	C58107
Participant History and Family History; General Health History	Cardiovascular myopathy disease type text	C58108
Participant History and Family History; General Health History	Cardiovascular arrhythmia disease type text	C58109
Participant History and Family History; General Health History	Family health problems chest history type	C58091
Participant History and Family History; General Health History	Chest lung breathing problem type text	C58092
Participant History and Family History; General Health History	Family health problems endocrine metabolic history type	C58093
Participant History and Family History; General Health History	Endocrine metabolic thyroid disease type text	C58094
Participant History and Family History; General Health History	Endocrine metabolic diabetes type text	C58110



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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Participant History and Family History; General Health History	Endocrine metabolic endocrine disorder type text	C58111
Participant History and Family History; General Health History	Family health problems gastrointestinal history type	C58095
Participant History and Family History; General Health History	Gastrointestinal stomach problems type text	C58096
Participant History and Family History; General Health History	Gastrointestinal intestine problems type text	C58113
Participant History and Family History; General Health History	Family health problems neurological history type	C58097
Participant History and Family History; General Health History	Neurological seizure type text	C58098
Participant History and Family History; General Health History	Neurological Alzheimer disease type text	C58114
Participant History and Family History; General Health History	Neurological sleep disorder type text	C58115
Participant History and Family History; General Health History	Neurological neuromuscular disorder type text	C58116
Participant History and Family History; General Health History	Family health problems rheumatological history type	C58099
Participant History and Family History; General Health History	Rheumatological arthritis type text	C58100
Participant History and Family History; General Health History	Family health problems psychological history type	C58101
Participant History and Family History; General Health History	Obsessive compulsive attention deficit disorder type text	C58102



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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Participant History and Family History; General Health History	Psychological other psychosis type text	C58117
Participant History and Family History; General Health History	Family health problems other condition history type	C58103
Participant History and Family History; General Health History	Other condition allergy type text	C58104
Participant History and Family History; General Health History	Other condition kidney problems type text	C58118
Participant History and Family History; General Health History	Other condition cancer type text	C58119
Participant History and Family History; General Health History	Other condition fatigue syndrome type text	C58121
Participant History and Family History; General Health History	Other condition other gynecological condition type text	C58122
Participant History and Family History; General Health History	Other condition other birth defect type text	C58123
Participant History and Family History; General Health History	Other condition other important condition type text	C58124
Assessments and Examinations; Physical/Neurological Examination	Cerebellar gait tiptoe assessment status	C57886
Assessments and Examinations; Physical/Neurological Examination	Cerebellar gait heel walk assessment status	C57888



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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Cerebellar gait normal gait assessment status	C57889
Assessments and Examinations; Physical/Neurological Examination	Cerebellar gait asymmetry arm swing assessment indicator	C57887
Assessments and Examinations; Physical/Neurological Examination	Cerebellar military Romberg assessment status	C57890
Assessments and Examinations; Physical/Neurological Examination	Cerebellar tandem Romberg assessment status	C57891
Assessments and Examinations; Physical/Neurological Examination	Cerebellar Romberg sway assessment indicator	C57892
Assessments and Examinations; Physical/Neurological Examination	Subject ID	C19247
Assessments and Examinations; Physical/Neurological Examination	Blood pressure diastolic measurement	C01507
Assessments and Examinations; Physical/Neurological Examination	Blood pressure systolic measurement	C01565
Assessments and Examinations; Physical/Neurological Examination	Heart rate	C01521

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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Respiratory rate	C01535
Assessments and Examinations; Physical/Neurological Examination	Standing time duration	C57989
Assessments and Examinations; Physical/Neurological Examination	Temperature measurement	C01539
Assessments and Examinations; Physical/Neurological Examination	Weight measurement	C01541
Assessments and Examinations; Physical/Neurological Examination	Height measurement	C01522
Assessments and Examinations; Physical/Neurological Examination	Neck circumference measurement	C57990
Assessments and Examinations; Physical/Neurological Examination	Waist circumference measurement	C14428
Assessments and Examinations; Physical/Neurological Examination	Hip circumference measurement	C14458
Assessments and Examinations; Physical/Neurological Examination	Head hair assessment status	C57991



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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Head scalp assessment status	C57992
Assessments and Examinations; Physical/Neurological Examination	Head summary assessment status	C57993
Assessments and Examinations; Physical/Neurological Examination	Comment text	C18027
Assessments and Examinations; Physical/Neurological Examination	Oral cavity mercury fillings assessment status	C57994
Assessments and Examinations; Physical/Neurological Examination	Oral cavity dentition assessment status	C57995
Assessments and Examinations; Physical/Neurological Examination	Oral cavity gums assessment status	C57996
Assessments and Examinations; Physical/Neurological Examination	Oral cavity oropharynx assessment status	C57997
Assessments and Examinations; Physical/Neurological Examination	Oral status summary assessment status	C57998
Assessments and Examinations; Physical/Neurological Examination	Neck supple assessment indicator	C57999



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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Neck masses assessment indicator	C58000
Assessments and Examinations; Physical/Neurological Examination	Neck jugular venous distension assessment status	C58001
Assessments and Examinations; Physical/Neurological Examination	Neck summary assessment status	C58003
Assessments and Examinations; Physical/Neurological Examination	Thyroid visible assessment indicator	C58004
Assessments and Examinations; Physical/Neurological Examination	Thyroid palpable assessment indicator	C58005
Assessments and Examinations; Physical/Neurological Examination	Thyroid nodules assessment indicator	C58006
Assessments and Examinations; Physical/Neurological Examination	Thyroid size assessment indicator	C58007
Assessments and Examinations; Physical/Neurological Examination	Thyroid summary assessment status	C58008
Assessments and Examinations; Physical/Neurological Examination	Eyes pupils equal assessment indicator	C58009

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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Eyes pupils round assessment indicator	C58010
Assessments and Examinations; Physical/Neurological Examination	Eyes pupils reactive assessment indicator	C58011
Assessments and Examinations; Physical/Neurological Examination	Eyes pupils accommodate assessment indicator	C58012
Assessments and Examinations; Physical/Neurological Examination	Eyes sclera assessment status	C58013
Assessments and Examinations; Physical/Neurological Examination	Eyes fundoscopic assessment status	C58014
Assessments and Examinations; Physical/Neurological Examination	Eyes photophobia assessment status	C58015
Assessments and Examinations; Physical/Neurological Examination	Eyes summary assessment status	C58016
Assessments and Examinations; Physical/Neurological Examination	Ear tympanic membrane assessment status	C58017
Assessments and Examinations; Physical/Neurological Examination	Ear canals assessment status	C58018



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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Ears summary assessment status	C58019
Assessments and Examinations; Physical/Neurological Examination	Nose nasal mucosa assessment status	C58020
Assessments and Examinations; Physical/Neurological Examination	Nose summary assessment status	C58021
Assessments and Examinations; Physical/Neurological Examination	Pharynx mucosa assessment status	C58022
Assessments and Examinations; Physical/Neurological Examination	Pharynx volume adequate assessment status	C58023
Assessments and Examinations; Physical/Neurological Examination	Pharynx tongue large assessment status	C58024
Assessments and Examinations; Physical/Neurological Examination	Pharynx TMJ tender assessment status	C58025
Assessments and Examinations; Physical/Neurological Examination	Pharynx summary assessment status	C58026
Assessments and Examinations; Physical/Neurological Examination	Chest shape assessment status	C58027

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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Chest summary assessment status	C58028
Assessments and Examinations; Physical/Neurological Examination	Lungs chest percussion assessment status	C58029
Assessments and Examinations; Physical/Neurological Examination	Lungs lung auscultation assessment status	C58030
Assessments and Examinations; Physical/Neurological Examination	Lungs summary assessment status	C58031
Assessments and Examinations; Physical/Neurological Examination	Heart palpation assessment status	C58032
Assessments and Examinations; Physical/Neurological Examination	Heart auscultation assessment status	C58033
Assessments and Examinations; Physical/Neurological Examination	Carotid artery auscultation pain assessment status	C58034
Assessments and Examinations; Physical/Neurological Examination	Abdominal artery auscultation assessment status	C58035
Assessments and Examinations; Physical/Neurological Examination	Heart large artery summary assessment status	C58036

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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Abdomen bowel sounds assessment status	C58037
Assessments and Examinations; Physical/Neurological Examination	Abdomen tenderness assessment indicator	C58038
Assessments and Examinations; Physical/Neurological Examination	Abdomen masses assessment indicator	C58039
Assessments and Examinations; Physical/Neurological Examination	Abdomen summary assessment status	C58040
Assessments and Examinations; Physical/Neurological Examination	Liver palpable assessment indicator	C58041
Assessments and Examinations; Physical/Neurological Examination	Liver palpable assessment indicator text	C58151
Assessments and Examinations; Physical/Neurological Examination	Liver summary assessment status	C58042
Assessments and Examinations; Physical/Neurological Examination	Spleen palpable assessment indicator	C58043
Assessments and Examinations; Physical/Neurological Examination	Spleen palpable assessment indicator text	C58152

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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Spleen summary assessment status	C58044
Assessments and Examinations; Physical/Neurological Examination	Extremities edematous assessment indicator	C58045
Assessments and Examinations; Physical/Neurological Examination	Extremities dependent rubor assessment indicator	C58046
Assessments and Examinations; Physical/Neurological Examination	Extremities pulses radial left assessment value	C58047
Assessments and Examinations; Physical/Neurological Examination	Extremities pulses radial right assessment value	C58048
Assessments and Examinations; Physical/Neurological Examination	Extremities pulses femoral left assessment value	C58049
Assessments and Examinations; Physical/Neurological Examination	Extremities pulses femoral right assessment value	C58050
Assessments and Examinations; Physical/Neurological Examination	Extremities pulses tibial dorsalis pedis artery left assessment value	C58051
Assessments and Examinations; Physical/Neurological Examination	Extremities pulses tibial dorsalis pedis artery right assessment value	C58052

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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Extremities summary assessment status	C58053
Assessments and Examinations; Physical/Neurological Examination	Joints muscles spine assessment status	C58054
Assessments and Examinations; Physical/Neurological Examination	Joints muscles shoulders assessment status	C58055
Assessments and Examinations; Physical/Neurological Examination	Joints muscles elbows assessment status	C58056
Assessments and Examinations; Physical/Neurological Examination	Joints muscles wrists assessment status	C58057
Assessments and Examinations; Physical/Neurological Examination	Joints muscles hands assessment status	C58058
Assessments and Examinations; Physical/Neurological Examination	Joints muscles hips assessment status	C58059
Assessments and Examinations; Physical/Neurological Examination	Joints muscles knees assessment status	C58060
Assessments and Examinations; Physical/Neurological Examination	Joints muscles ankles assessment status	C58061



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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Joints muscles feet assessment status	C58062
Assessments and Examinations; Physical/Neurological Examination	Joints muscles summary assessment status	C58063
Assessments and Examinations; Physical/Neurological Examination	Skin jaundice assessment status	C58064
Assessments and Examinations; Physical/Neurological Examination	Skin acne assessment status	C58065
Assessments and Examinations; Physical/Neurological Examination	Skin ulcerations assessment status	C58066
Assessments and Examinations; Physical/Neurological Examination	Skin rash assessment status	C58067
Assessments and Examinations; Physical/Neurological Examination	Skin lesions assessment status	C58068
Assessments and Examinations; Physical/Neurological Examination	Skin too dry assessment status	C58069
Assessments and Examinations; Physical/Neurological Examination	Skin summary assessment status	C58070

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Lymph nodes cervical posterior assessment status	C58071
Assessments and Examinations; Physical/Neurological Examination	Lymph nodes cervical anterior assessment status	C58072
Assessments and Examinations; Physical/Neurological Examination	Lymph nodes supraclavicular assessment status	C58073
Assessments and Examinations; Physical/Neurological Examination	Lymph nodes supraclavicular assessment status text	C58163
Assessments and Examinations; Physical/Neurological Examination	Lymph nodes axillary assessment status	C58074
Assessments and Examinations; Physical/Neurological Examination	Lymph nodes inguinal assessment status	C58075
Assessments and Examinations; Physical/Neurological Examination	Lymph nodes summary assessment status	C58076
Assessments and Examinations; Physical/Neurological Examination	Cerebellar finger nose finger assessment status	C57885
Assessments and Examinations; Physical/Neurological Examination	Cerebellar gait normal gait assessment status	C57889

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Cerebellar heel shin assessment status	C57884
Assessments and Examinations; Physical/Neurological Examination	Cerebellar tandem stance gait assessment status	C58077
Assessments and Examinations; Physical/Neurological Examination	Cerebellar tandem stance gait augmentation assessment status	C58078
Assessments and Examinations; Physical/Neurological Examination	Cerebellar tandem Romberg assessment status	C57891
Assessments and Examinations; Physical/Neurological Examination	Hand preference type	C00023
Assessments and Examinations; Physical/Neurological Examination	Cerebellar summary assessment status	C57893
Assessments and Examinations; Physical/Neurological Examination	Cranial nerve visual field assessment status	C57895
Assessments and Examinations; Physical/Neurological Examination	Cranial nerve shoulder raise assessment status	C57896
Assessments and Examinations; Physical/Neurological Examination	Cranial nerve auditory assessment status	C57897



**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Cranial nerve extra ocular muscle assessment status	C57894
Assessments and Examinations; Physical/Neurological Examination	Cranial nerve facial expression assessment status	C57898
Assessments and Examinations; Physical/Neurological Examination	Cranial nerve summary assessment status	C57900
Assessments and Examinations; Physical/Neurological Examination	Sensory light touch assessment status	C57901
Assessments and Examinations; Physical/Neurological Examination	Sensory pinprick assessment status	C57902
Assessments and Examinations; Physical/Neurological Examination	Sensory vibration assessment status	C57903
Assessments and Examinations; Physical/Neurological Examination	Sensory proprioception assessment status	C57904
Assessments and Examinations; Physical/Neurological Examination	Sensory summary assessment status	C57905
Assessments and Examinations; Physical/Neurological Examination	Muscle tone assessment status	C57906

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Muscle atrophy assessment status	C57907
Assessments and Examinations; Physical/Neurological Examination	Muscle rise chair tiptoe assessment status	C57908
Assessments and Examinations; Physical/Neurological Examination	Muscle involuntary movement assessment status	C57909
Assessments and Examinations; Physical/Neurological Examination	Muscle proximal muscle strength assessment status	C57910
Assessments and Examinations; Physical/Neurological Examination	Muscle distal muscle strength assessment status	C57911
Assessments and Examinations; Physical/Neurological Examination	Muscle strength summary assessment status	C57912
Assessments and Examinations; Physical/Neurological Examination	Reflex bicep assessment status	C57913
Assessments and Examinations; Physical/Neurological Examination	Reflex triceps assessment status	C57988
Assessments and Examinations; Physical/Neurological Examination	Reflex patellar assessment status	C57915

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Reflex ankle jerk assessment status	C57916
Assessments and Examinations; Physical/Neurological Examination	Reflex Babinski assessment status	C57917
Assessments and Examinations; Physical/Neurological Examination	Reflex summary assessment status	C57919
Assessments and Examinations; Physical/Neurological Examination	Neurologic summary assessment status	C57920
Assessments and Examinations; Physical/Neurological Examination	Mental psychological affect assessment status	C58079
Assessments and Examinations; Physical/Neurological Examination	Mental psychological speech assessment status	C58080
Assessments and Examinations; Physical/Neurological Examination	Mental psychological orientation assessment status	C58081
Assessments and Examinations; Physical/Neurological Examination	Mental psychological thoughts assessment status	C58082
Assessments and Examinations; Physical/Neurological Examination	Mental psychological summary assessment status	C58083



**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Physical exam assessment other text	C58084
Assessments and Examinations; Physical/Neurological Examination	Clinical impressions differential diagnoses text	C58085
Assessments and Examinations; Physical/Neurological Examination	Temperature measurement	C01539
Assessments and Examinations; Physical/Neurological Examination	Temperature unit of measure	C01580
Assessments and Examinations; Physical/Neurological Examination	Oropharyngeal exam status	C57937
Assessments and Examinations; Physical/Neurological Examination	Oropharyngeal exam abnormal result text	C57938
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam anterior cervical status	C57939
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam posterior cervical status	C57940
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam submandibular status	C57941

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam occipital status	C57942
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam supraclavicular status	C57943
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam axillary status	C57944
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam inguinal status	C57945
Assessments and Examinations; Physical/Neurological Examination	Lymph node exam abnormal result text	C57946
Assessments and Examinations; Physical/Neurological Examination	Skin exam result status	C57947
Assessments and Examinations; Physical/Neurological Examination	Skin exam abnormal result text	C57948
Assessments and Examinations; Physical/Neurological Examination	Skin exam comments text	C57949
Assessments and Examinations; Physical/Neurological Examination	Hair exam result status	C57950



**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Hair exam abnormal result text	C57951
Assessments and Examinations; Physical/Neurological Examination	Hair exam comments text	C57952
Assessments and Examinations; Physical/Neurological Examination	Joint exam tender joint count	C57953
Assessments and Examinations; Physical/Neurological Examination	Joint exam swollen joint count	C57954
Assessments and Examinations; Physical/Neurological Examination	Joint exam damaged joint count	C57955
Assessments and Examinations; Physical/Neurological Examination	Wong-Baker FACES - Pain rating scale	C22622
Assessments and Examinations; Physical/Neurological Examination	Beighton Score - Motion thumb forearm assessment score	C21684
Assessments and Examinations; Physical/Neurological Examination	Beighton Score - Motion finger bend back score	C21685
Assessments and Examinations; Physical/Neurological Examination	Fibromyalgia diagnosis indicator	C58459

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Physical/Neurological Examination	Fibromyalgia diagnosis criterion type	C58460
Assessments and Examinations; Physical/Neurological Examination	Beighton Score - Motion elbow hyperextend score	C21686
Assessments and Examinations; Physical/Neurological Examination	Beighton Score - Motion knee hyperextend score	C21687
Assessments and Examinations; Physical/Neurological Examination	Beighton Score - Motion palm flat leg straight score	C21688
Assessments and Examinations; Physical/Neurological Examination	Beighton Score - Total score	C21689
Assessments and Examinations; Post-Exertional Malaise	Post exertional malaise external stimulus induce type	C57042
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise determine stimulus research participant type	C57043
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise researcher determine stimulus type description text	C57044
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise researcher determine stimulus protocol description text	C57045

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise study participant determine stimulus measurement type	C57046
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise termination stimulus indicator	C57047
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise study participant determine termination criteria type	C57048
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise researcher determine termination type	C57049
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise maximum heart rate percentage value	C57050
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise duration frequency related text	C57051
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise stimulus relate text	C57052
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise symptom examine indicator	C57053
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise additional symptom text	C57054
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise outcome measure time indicator	C57055



**Summary of Core/Supplemental – Highly Recommended Recommendations:  
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Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise other time point outcome measure text	C57056
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise correlation objective outcome subjective measure indicator	C57057
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise outcome measure type	C57058
Assessments and Examinations; Post-Exertional Malaise	Post-exertional malaise confounding activity indicator	C57059
Assessments and Examinations; Autonomic	Assessment performed date	C19500
Assessments and Examinations; Autonomic	Medication prior or concomitant name	C02014
Assessments and Examinations; Autonomic	Lab test participant position type	C19361
Assessments and Examinations; Autonomic	Position held minute text	C58394
Assessments and Examinations; Autonomic	Heart rate	C01521
Assessments and Examinations; Autonomic	Blood pressure measurement	C19565
Assessments and Examinations; Autonomic	Comment text	C18027

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Laboratory test immune name	C58174
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Lab specimen collection date and time	C01701
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Sample collection processing elapse time interval	C58402
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Specimen storage temperature value	C55009
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Medication baseline modification before study start indicator	C58403
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Serum plasma sample collection processing elapse time interval	C58412
Assessments and Examinations; Laboratory Tests and Biospecimens/Biomarkers	Serum plasma sample storage temperature value	C58413
Treatment/Intervention Data; Drugs	Study protocol name	C19256
Treatment/Intervention Data; Drugs	Site name	C17402
Treatment/Intervention Data; Drugs	Subject ID	C19247

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Treatment/Intervention Data; Drugs	Assessment performed date	C19500
Treatment/Intervention Data; Drugs	Medication prior or concomitant name	C02014
Treatment/Intervention Data; Drugs	Medication prior or concomitant dose	C02006
Treatment/Intervention Data; Drugs	Medication prior or concomitant dose unit of measure UCUM code	C02013
Treatment/Intervention Data; Drugs	Medication prior or concomitant route type	C02015
Treatment/Intervention Data; Drugs	Medication prior or concomitant dose frequency	C02011
Treatment/Intervention Data; Drugs	Medication prior or concomitant start date and time	C02016
Treatment/Intervention Data; Drugs	Medication actual use schedule frequency	C58389
Treatment/Intervention Data; Drugs	Medication prior or concomitant indication text	C02024
Treatment/Intervention Data; Drugs	Medication symptom status	C58390
Treatment/Intervention Data; Drugs	Other treatments reason type	C58129
Treatment/Intervention Data; Drugs	Other treatments reason type text	C58395

**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Treatment/Intervention Data; Drugs	Other treatments date	C58130
Treatment/Intervention Data; Drugs	Other treatments result type	C58131
Outcomes and End Points; Sleep	Site name	C17402
Outcomes and End Points; Sleep	Subject ID	C19247
Outcomes and End Points; Sleep	ME/CFS prior history sleep problem indicator	C57101
Outcomes and End Points; Sleep	Sleep problem diagnosis type	C57102
Outcomes and End Points; Sleep	Issue present no diagnosis type	C57103
Outcomes and End Points; Sleep	Acclimation period before study indicator	C57104
Outcomes and End Points; Sleep	Acclimation process description text	C57105
Outcomes and End Points; Sleep	Medication help sleep problem indicator	C57106
Outcomes and End Points; Sleep	Medication taken neurologic psychiatric affect sleep indicator	C57107
Outcomes and End Points; Sleep	Medication neurologic psychiatric type text	C57108
Outcomes and End Points; Sleep	Medication affect sleep stop indicator	C57109



**Summary of Core/Supplemental – Highly Recommended Recommendations:  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs**

Domain; Sub-Domain	Supplemental – Highly Recommended Data element	CDE ID
Outcomes and End Points; Sleep	Medication stopped other instructions given specify text	C58439
Outcomes and End Points; Sleep	Prior to study medication stopped duration	C58438
Outcomes and End Points; Sleep	Sleep wake time correspond subject sleep wake time indicator	C57110



## Summary of Core/Supplemental – Highly Recommended Recommendations: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs

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### Core Instruments:

- DePaul Symptom Questionnaire (DSQ) **OR** ME/CFS Symptom Checklist

### Supplemental – Highly Recommended (study focus dependent) Instruments/CRFs:

- Composite Autonomic Symptom Scale
- Child Health Questionnaire
- Sleep Assessment Questionnaire – Moldofsky
- Magnetic Resonance Imaging (MRI)\*
- Functional Magnetic Resonance Imaging (fMRI)\*
- Diffusion Tensor Imaging (DTI)\*
- Magnetic Resonance Spectroscopy (MRS)\*
- Positron Emission Tomography (PET)\*
- Magnetoencephalography (MEG)\*
- Non-Quantitative Electroencephalography (EEG)\*
- Quantitative Electroencephalography (qEEG)\*
- Low Resolution Electromagnetic Tomography (LORETA)\*
- Word Reading Subtest of the Wide Range Achievement Test (WRAT-4)
- Paced Auditory Serial Addition Test (PASAT)
- Stroop Test
- Children's Paced Auditory Serial Addition Task (ChiPASAT)
- Beck Anxiety Inventory (BAI)
- Beck Depression Inventory II (BDI-II)
- Delis-Kaplan Executive Function System (D-KEFS) Recommended modules: Color-Word-Interference Test, Trail Making Test, Verbal Fluency
- Edinburgh Handedness Inventory
- California Verbal Learning Test - Second Edition (CVLT-II)

## Summary of Core/Supplemental – Highly Recommended Recommendations: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs

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- California Verbal Learning Test - Children (CVLT-C)
- Rey-Osterrieth Complex Figure Test (ROCF)
- Fatigue Severity Scale (FSS)
- Brief Pain Inventory (Short Form) (BPI)
- Revised Fibromyalgia Impact Questionnaire (FIQR)
- McGill Pain Questionnaire (MPQ)
- Faces Pain Scale - Revised (FPS-R)

\*Note: CDEs on Imaging CRFs are all Supplemental – Highly Recommended and are not listed individually.

For the complete list of NINDS CDE recommendations for ME/CFS, please see the [NINDS CDE website](#).