Supplement A. DePaul Symptom Questionnaire (DSQ-1)

This document contains the following material:

- 1. Case definition scoring rules and associated symptoms for the following criteria:
 - a. Fukuda et al. (1994)
 - b. Canadian ME/CFS (Carruthers et al., 2003)
 - c. ME-ICC (Carruthers et al., 2011)
 - d. Institute of Medicine (IOM, 2015)
- 2. Syntax for the following case definitions:
 - a. Fukuda et al. (1994)
 - b. Canadian ME/CFS (Carruthers et al., 2003)
 - c. ME-ICC (Carruthers et al., 2011)
 - d. Institute of Medicine (IOM, 2015)
- 3. Hard copy of the DSQ-1 and the SF-36

The DePaul Symptom Questionnaire (DSQ-1) can be downloaded from the REDCap shared library. You can view the instrument here: https://redcap.is.depaul.edu/surveys/?s=H443P9TPFX

DSQ-1 Case Definition Criteria:

Fukuda (Fukuda et al., 1994)

- Substantial Reduction in Functioning (must meet 2 of the following 3 SF-36 score cutoffs):
 - o Role Physical <= 50
 - Social Functioning <= 62.5
 - Vitality <= 35
- 6+ months of fatigue (Question 69)
 - o Fatigue <u>not</u> lifelong (<u>Exclude</u> if: Question 67 = "Yes" <u>and</u> Question 69 = "Had problem since childhood/adolescence"... <u>and</u> Question 77 = "Over 3 or more years")
 - Fatigue <u>not</u> the result of exertion: (<u>Exclude</u> if: Sum of Question 89a and 89d >=
 60)
- At least 1 symptom (frequency and severity ratings >=1) from at least 4 symptom domains:
 - o Memory / Concentration (Questions 36-39; 43-44)
 - Unrefreshing Sleep (Question 19)
 - o Joint Pain (Question 26)
 - o Tender / Sore Lymph Nodes (Question 63)
 - o Muscle Aches (Question 25)
 - o Post-Exertional Malaise (Questions 14-18)
 - o Headaches (Question 31; must also be of a new place/type, Question 68)
 - o Sore Throat (Question 62)

Canadian Consensus Criteria (CCC Case Definition, Carruthers et al., 2003)

- Substantial Reduction in Functioning (must meet 2 of the following 3 SF-36 score cutoffs):
 - o Role Physical <= 50
 - o Social Functioning <= 62.5
 - Vitality <= 35
 - Fatigue:
 - o 6+ months of fatigue (Question 69)
 - \circ Fatigue frequency and severity ≥ 2 (Question 13)
 - Fatigue <u>not</u> lifelong (<u>Exclude</u> if: Question 67 = "Yes" <u>and</u> Question 69 = "Had problem since childhood/adolescence"... <u>and</u> Question 77 = "Over 3 or more years")
 - Fatigue <u>not</u> the result of exertion: (<u>Exclude</u> if: Sum of Question 89a and 89d >=
 60)
 - Post-Exertional Malaise (At least 1 symptom (frequency and severity ratings >=2) from questions 14-18)
 - Sleep Problems (At least 1 symptom (frequency and severity ratings >=2) from questions 19-24)
 - Pain (At least 1 symptom (frequency and severity ratings >=2) from questions 25-31)
 - Neurological / Cognitive Problems (At least 2 symptoms (frequency and severity ratings >=2) from questions 32-44)
 - At least 1 symptom (frequency and severity ratings >=2) from 2 of the 3 following areas:
 - o Autonomic (Questions 45-51)
 - o Neuroendocrine (Questions 52-61)
 - o Immune (Questions 62-66)

Myalgic Encephalomyelitis International Consensus Criteria (ME-ICC; Carruthers et al., 2011)

- 50% reduction in activity level ("Yes" to Question 97)
- Post Exertional Malaise (At least one symptom (frequency and severity ratings >=2) from question 14-18)
- At least 1 symptom (frequency and severity ratings >=2) from 3 of the following 4 symptom domains:
 - o Neurocognitive: Questions 36-44
 - o Pain: Questions 25-28; 31
 - o Sleep Disturbance: Questions 19-24
 - o Neurosensory, Perceptual, and Motor Disturbance: Questions 32-35; 48
- At least 1 symptom (frequency and severity ratings >=2; except for Question 98, which requires a response of "Yes") from 3 of the following 5 symptom domains:
 - o Flu-like: Questions 62-65
 - o Gastrointestinal: Questions 29-30; 46-47
 - o Genitourinary: Question 45
 - o Sensitivities: Questions 61, 66
 - Susceptibility to Viral Infections: Question 98
- At least 1 symptom (frequency and severity ratings >=2; except for Question 99, which requires a response of "Yes") from 1 of the following 4 symptom domains:
 - o Cardiovascular: Questions 50-51
 - o Respiratory: Question 49
 - Loss of thermostatic ability: Questions 54-60
 - o Temperature intolerance: Question 99

IOM Clinical Case Definition (IOM, 2015):

- Substantial Reduction in functioning (must meet 2 of the following 3 SF-36 score cutoffs):
 - o Role Physical <= 50
 - Social Functioning <= 62.5
 - Vitality <= 35
- 6+ months of fatigue (Question 69)
 - Fatigue <u>not</u> lifelong (<u>Exclude</u> if: Question 67 = "Yes" <u>and</u> Question 69 = "Had problem since childhood/adolescence"... <u>and</u> Question 77 = "Over 3 or more years")
 - Fatigue <u>not</u> the result of exertion: (<u>Exclude</u> if: Sum of Question 89a and 89d >=
 60)
- Post-Exertional Malaise (At least 1 symptom (frequency and severity ratings >= 2) from questions 14-18)
- Unrefreshing Sleep (At least 1 symptom (frequency and severity ratings >= 2) from questions 19-22; 24)
- At least 1 symptom (frequency and severity ratings >= 2) from 1 of the following 2 symptom domains:
 - o Cognitive Impairment (Questions 36-40; 43-44)
 - o Orthostatic Intolerance (Questions 48-51)

DSQ-1 SPSS Case Definition Syntax:

Scoring Note: To determine which variables are associated with which items, note that variable names utilize the items numbers present in the questionnaire.

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*************************
                                *DSO-1*.
                        *Fukuda et al. (1994) Criteria*.
****************************
***Substantial Reduction in Functioning Criteria, SF-36***.
***To score the SF-36, use scoring rules found here:
***https://www.rand.org/health/surveys tools/mos/36-item-short-form/scoring.html***.
***Variable names are equivalent to SF-36 Subscale Names***.
COMPUTE Fukuda RP = 0.
EXECUTE.
IF (RolePhysical \leq 50) Fukuda RP = 1.
EXECUTE.
COMPUTE Fukuda SF = 0.
EXECUTE.
IF (SocialFunctioning \leq 62.5) Fukuda SF = 1.
EXECUTE.
```

COMPUTE $Fukuda_V = 0$.

EXECUTE.

IF (Vitality ≤ 35) Fukuda V = 1.

EXECUTE.

COMPUTE Fukuda SR=0.

EXECUTE.

IF $(SUM(Fukuda_RP, Fukuda_SF, Fukuda_V) \ge 2) Fukuda_SR = 1$.

EXECUTE.

```
***DSQ-1 Symptom Scoring***.
```

*Fatigue, Not Lifelong, Not Result of Exertion *.

COMPUTE Fukuda Six = 0.

EXECUTE.

IF $((dsq_69 = 2) | (dsq_69 = 3) | (dsq_69 = 4) | (dsq_69 = 5))$ Fukuda_Six = 1.

COMPUTE Fukuda Life = 0.

EXECUTE.

IF ((dsq 67 = 1) & (dsq 69 = 5) & (dsq 77 = 7)) Fukuda Life = 1.

EXECUTE.

COMPUTE Fukuda Exert = 0.

EXECUTE.

 $IF((SUM(dsq 89a, dsq 89d) \ge 60))$ Fukuda Exert = 1.

EXECUTE.

COMPUTE Fukuda Fatigue = 0.

EXECUTE.

IF ((Fukuda_Six = 1) & (Fukuda_Life = 0) & (Fukuda_Exert = 0)) Fukuda_Fatigue = 1.

EXECUTE.

Post-Exertional Malaise.

COMPUTE Fukuda 14 = 0.

EXECUTE.

IF $((dsq 14f \ge 1) & (dsq 14s \ge 1))$ Fukuda 14 = 1.

EXECUTE.

COMPUTE Fukuda 15 = 0.

EXECUTE.

IF $((dsq 15f \ge 1) & (dsq 15s \ge 1))$ Fukuda_15 = 1.

EXECUTE.

COMPUTE Fukuda 16 = 0.

EXECUTE.

IF $((dsq \ 16f \ge 1) \& (dsq \ 16s \ge 1))$ Fukuda 16 = 1.

EXECUTE.

COMPUTE Fukuda 17 = 0.

EXECUTE.

IF $((dsq 17f \ge 1) & (dsq 17s \ge 1))$ Fukuda 17 = 1.

EXECUTE.

COMPUTE Fukuda 18 = 0.

EXECUTE.

IF $((dsq 18f \ge 1) & (dsq 18s \ge 1))$ Fukuda 18 = 1.

EXECUTE.

COMPUTE Fukuda PEM = 0.

EXECUTE.

IF(SUM(Fukuda_14, Fukuda_15, Fukuda_16, Fukuda_17, Fukuda_18) >= 1) Fukuda_PEM = 1.

EXECUTE.

Unrefreshing Sleep.

COMPUTE Fukuda Sleep = 0.

```
EXECUTE.
```

IF $((dsq_19f >= 1) & (dsq_19s >= 1))$ Fukuda_Sleep = 1. EXECUTE.

Muscle Aches.

COMPUTE Fukuda Muscle = 0.

EXECUTE.

IF $((dsq_25f >= 1) & (dsq_25s >= 1))$ Fukuda_Muscle = 1.

EXECUTE.

Joint Pain.

COMPUTE Fukuda Joint = 0.

EXECUTE.

IF $((dsq_26f >= 1) & (dsq_26s >= 1))$ Fukuda_Joint = 1.

EXECUTE.

Headaches.

COMPUTE Fukuda Headache = 0.

EXECUTE.

IF $((dsq_31f >= 1) & (dsq_31s >= 1) & (dsq_68 = 1))$ Fukuda_Headache = 1. EXECUTE.

Memory and Concentration.

COMPUTE Fukuda 36 = 0.

EXECUTE.

IF ((dsq 36f >= 1) & (dsq 36s >= 1)) Fukuda 36 = 1.

EXECUTE.

COMPUTE Fukuda 37 = 0.

EXECUTE.

IF $((dsq 37f \ge 1) & (dsq 37s \ge 1))$ Fukuda 37 = 1.

EXECUTE.

COMPUTE Fukuda 38 = 0.

EXECUTE.

IF $((dsq 38f \ge 1) & (dsq 38s \ge 1))$ Fukuda 38 = 1.

EXECUTE.

COMPUTE Fukuda 39 = 0.

EXECUTE.

IF ((dsq 39f >= 1) & (dsq 39s >= 1)) Fukuda_39 = 1.

EXECUTE.

COMPUTE Fukuda 43 = 0.

EXECUTE.

IF $((dsq \ 43f \ge 1) \& (dsq \ 43s \ge 1))$ Fukuda 43 = 1.

EXECUTE.

COMPUTE Fukuda_44 = 0.

EXECUTE.

IF $((dsq_44f \ge 1) & (dsq_44s \ge 1))$ Fukuda_44 = 1.

EXECUTE.

COMPUTE Fukuda Memory = 0.

EXECUTE.

IF (SUM(Fukuda_36, Fukuda_37, Fukuda_38, Fukuda_39, Fukuda_43, Fukuda_44) >= 1) Fukuda Memory = 1.

EXECUTE.

* Sore Throat*.

COMPUTE Fukuda Throat = 0.

EXECUTE.

IF $((dsq 62f \ge 1) & (dsq 62s \ge 1))$ Fukuda Throat = 1.

EXECUTE.

Lymph Nodes.

COMPUTE Fukuda Lymph = 0.

EXECUTE.

IF $((dsq_63f \ge 1) & (dsq_63s \ge 1))$ Fukuda_Lymph = 1.

EXECUTE.

Fukuda Case Definition.

COMPUTE Fukuda = 0.

EXECUTE.

IF((Fukuda_SR = 1) & (Fukuda_Fatigue = 1) & (SUM(Fukuda_PEM, Fukuda_Sleep, Fukuda_Muscle, Fukuda_Joint, Fukuda_Headache, Fukuda_Memory, Fukuda_Throat, Fukuda Lymph) >= 4)) Fukuda = 1.

EXECUTE.

VALUE LABELS

Fukuda

0 'Does Not Meet Fukuda Criteria'

1 'Meets Fukuda Criteria'.

******************************* *DSQ-1*. *Canadian Clinical ME/CFS Criteria (CCC; Carruthers et al., 2003)*. *************************** ***Substantial Reduction in Functioning Criteria, SF-36***. ***To score the SF-36, use scoring rules found here: ***https://www.rand.org/health/surveys tools/mos/36-item-short-form/scoring.html***. ***Variable names are equivalent to SF-36 Subscale Names***. COMPUTE CCC RP = 0. EXECUTE. IF (RolePhysical ≤ 50) CCC RP = 1. EXECUTE. COMPUTE CCC SF = 0. EXECUTE. IF (SocialFunctioning <= 62.5) CCC_SF = 1. EXECUTE. COMPUTE CCC V = 0. EXECUTE. IF (Vitality ≤ 35) CCC V = 1. EXECUTE. COMPUTE CCC SR=0. EXECUTE. IF (SUM(CCC RP, CCC SF, CCC V) \geq 2) CCC SR = 1. EXECUTE. ***DSQ-1 Symptom Scoring***. *Fatigue, Not Lifelong, Not Result of Exertion*. COMPUTE CCC Six = 0. EXECUTE. IF ((dsq 69 = 2) | (dsq 69 = 3) | (dsq 69 = 4) | (dsq 69 = 5)) CCC Six = 1. EXECUTE.

COMPUTE CCC 13 = 0.

EXECUTE.

IF $((dsq 13f \ge 2) \& (dsq 13s \ge 2))$ CCC 13 = 1.

EXECUTE.

COMPUTE CCC Life = 0.

EXECUTE.

IF ((dsq 67 = 1) & (dsq 69 = 5) & (dsq 77 = 7)) CCC Life = 1.

COMPUTE CCC Exert = 0. EXECUTE. $IF((SUM(dsq 89a, dsq 89d) \ge 60)) CCC Exert = 1.$ EXECUTE. COMPUTE CCC Fatigue = 0. EXECUTE. IF ((CCC Six = 1) & (CCC 13 = 1) & (CCC Life = 0) & (CCC Exert = 0)) CCC Fatigue = 1. EXECUTE. *Post-Exertional Malaise*. COMPUTE CCC 14 = 0. EXECUTE. IF $((dsq 14f \ge 2) & (dsq 14s \ge 2))$ CCC 14 = 1. EXECUTE. COMPUTE CCC 15 = 0. EXECUTE. IF $((dsq 15f \ge 2) & (dsq 15s \ge 2))$ CCC 15 = 1. EXECUTE. COMPUTE CCC 16 = 0. EXECUTE. IF $((dsq \ 16f \ge 2) \& (dsq \ 16s \ge 2))$ CCC 16 = 1. EXECUTE. COMPUTE CCC 17 = 0. EXECUTE. IF $((dsq 17f \ge 2) & (dsq 17s \ge 2))$ CCC 17 = 1. EXECUTE. COMPUTE CCC 18 = 0. EXECUTE. IF $((dsq \ 18f \ge 2) \& (dsq \ 18s \ge 2))$ CCC 18 = 1. EXECUTE. COMPUTE CCC PEM = 0. EXECUTE. IF(SUM(CCC 14, CCC 15, CCC 16, CCC 17, CCC 18) \geq 1) CCC PEM = 1. EXECUTE. *Sleep*.

COMPUTE $CCC_19 = 0$.

EXECUTE.

IF $((dsq_19f >= 2) & (dsq_19s >= 2)) CCC_19 = 1.$

COMPUTE CCC 20 = 0.

EXECUTE.

IF $((dsq_20f >= 2) & (dsq_20s >= 2)) CCC_20 = 1.$

EXECUTE.

COMPUTE CCC 21 = 0.

EXECUTE.

IF $((dsq 21f \ge 2) & (dsq 21s \ge 2))$ CCC 21 = 1.

EXECUTE.

COMPUTE CCC 22 = 0.

EXECUTE.

IF $((dsq_22f >= 2) & (dsq_22s >= 2)) CCC_22 = 1.$

EXECUTE.

COMPUTE CCC 23 = 0.

EXECUTE.

IF $((dsq 23f \ge 2) & (dsq 23s \ge 2))$ CCC 23 = 1.

EXECUTE.

COMPUTE CCC 24 = 0.

EXECUTE.

IF $((dsq 24f \ge 2) & (dsq 24s \ge 2))$ CCC 24 = 1.

EXECUTE.

COMPUTE CCC Sleep = 0.

EXECUTE.

IF(SUM(CCC_19, CCC_20, CCC_21, CCC_22, CCC_23, CCC_24) >= 1) CCC_Sleep = 1.

EXECUTE.

Pain.

COMPUTE CCC 25 = 0.

EXECUTE.

IF $((dsq \ 25f \ge 2) \& (dsq \ 25s \ge 2))$ CCC 25 = 1.

EXECUTE.

COMPUTE $CCC_26 = 0$.

EXECUTE.

IF $((dsq \ 26f \ge 2) \& (dsq \ 26s \ge 2))$ CCC 26 = 1.

EXECUTE.

COMPUTE CCC 27 = 0.

EXECUTE.

IF $((dsq \ 27f \ge 2) \& (dsq \ 27s \ge 2))$ CCC $\ 27 = 1$.

EXECUTE.

COMPUTE CCC 28 = 0.

IF ((dsq_28f>= 2) & (dsq_28s>= 2)) CCC_28 = 1. EXECUTE.

COMPUTE CCC 29 = 0.

EXECUTE.

IF $((dsq_29f \ge 2) & (dsq_29s \ge 2))$ CCC_29 = 1.

EXECUTE.

COMPUTE CCC 30 = 0.

EXECUTE.

IF ((dsq 30f >= 2) & (dsq 30s >= 2)) CCC 30 = 1.

EXECUTE.

COMPUTE CCC 31 = 0.

EXECUTE.

IF $((dsq 31f \ge 2) & (dsq 31s \ge 2) & (dsq 68 = 1))$ CCC 31 = 1.

EXECUTE.

COMPUTE CCC Pain = 0.

EXECUTE.

IF(SUM(CCC_25, CCC_26, CCC_27, CCC_28, CCC_29, CCC_30, CCC_31) >= 1) CCC_Pain = 1.

EXECUTE.

Neurocognitive.

COMPUTE CCC 32 = 0.

EXECUTE.

IF $((dsq 32f \ge 2) & (dsq 32s \ge 2))$ CCC 32 = 1.

EXECUTE.

COMPUTE CCC 33 = 0.

EXECUTE.

IF $((dsq 33f \ge 2) & (dsq 33s \ge 2))$ CCC 33 = 1.

EXECUTE.

COMPUTE CCC 34 = 0.

EXECUTE.

IF $((dsq 34f \ge 2) & (dsq 34s \ge 2))$ CCC 34 = 1.

EXECUTE.

COMPUTE CCC 35 = 0.

EXECUTE.

IF $((dsq 35f \ge 2) & (dsq 35s \ge 2))$ CCC 35 = 1.

EXECUTE.

COMPUTE CCC 36 = 0.

EXECUTE.

IF $((dsq 36f \ge 2) & (dsq 36s \ge 2))$ CCC 36 = 1.

COMPUTE CCC 37 = 0.

EXECUTE.

IF $((dsq_37f \ge 2) & (dsq_37s \ge 2)) CCC_37 = 1.$

EXECUTE.

COMPUTE CCC 38 = 0.

EXECUTE.

IF $((dsq 38f \ge 2) & (dsq_38s \ge 2)) CCC_38 = 1.$

EXECUTE.

COMPUTE CCC 39 = 0.

EXECUTE.

IF ((dsq 39f >= 2) & (dsq 39s >= 2)) CCC 39 = 1.

EXECUTE.

COMPUTE CCC 40 = 0.

EXECUTE.

IF $((dsq \ 40f \ge 2) \& (dsq \ 40s \ge 2))$ CCC 40 = 1.

EXECUTE.

COMPUTE CCC_41 = 0.

EXECUTE.

IF $((dsq 41f \ge 2) & (dsq 41s \ge 2))$ CCC 41 = 1.

EXECUTE.

COMPUTE CCC 42 = 0.

EXECUTE.

IF $((dsq \ 42f \ge 2) \& (dsq \ 42s \ge 2))$ CCC 42 = 1.

EXECUTE.

COMPUTE CCC 43 = 0.

EXECUTE.

IF $((dsq \ 43f \ge 2) \& (dsq \ 43s \ge 2))$ CCC 43 = 1.

EXECUTE.

COMPUTE CCC 44 = 0.

EXECUTE.

IF $((dsq 44f \ge 2) & (dsq 44s \ge 2))$ CCC 44 = 1.

EXECUTE.

COMPUTE CCC Neurocog = 0.

EXECUTE.

IF(SUM(CCC 32, CCC 33, CCC 34, CCC 35, CCC 36, CCC 37, CCC 38, CCC 39,

CCC 40, CCC 41, CCC 42, CCC 43, CCC 44) >= 2) CCC Neurocog = 1.

EXECUTE.

Autonomic.

COMPUTE CCC 45 = 0.

EXECUTE.

IF $((dsq_45f >= 2) & (dsq_45s >= 2))$ CCC_45 = 1.

EXECUTE.

COMPUTE CCC 46 = 0.

EXECUTE.

IF $((dsq_46f \ge 2) & (dsq_46s \ge 2)) CCC_46 = 1.$

EXECUTE.

COMPUTE CCC 47 = 0.

EXECUTE.

IF ((dsq 47f >= 2) & (dsq 47s >= 2)) CCC 47 = 1.

EXECUTE.

COMPUTE CCC 48 = 0.

EXECUTE.

IF $((dsq \ 48f \ge 2) \& (dsq \ 48s \ge 2))$ CCC 48 = 1.

EXECUTE.

COMPUTE CCC 49 = 0.

EXECUTE.

IF ((dsq 49f >= 2) & (dsq 49s >= 2)) CCC 49 = 1.

EXECUTE.

COMPUTE CCC 50 = 0.

EXECUTE.

IF $((dsq 50f \ge 2) & (dsq 50s \ge 2))$ CCC 50 = 1.

EXECUTE.

COMPUTE CCC_51 = 0.

EXECUTE.

IF $((dsq 51f \ge 2) & (dsq 51s \ge 2))$ CCC 51 = 1.

EXECUTE.

COMPUTE $CCC_Auto = 0$.

EXECUTE.

IF(SUM(CCC_45, CCC_46, CCC_47, CCC_48, CCC_49, CCC_50, CCC_51) >= 1) CCC_Auto

= 1.

EXECUTE.

Neuroendocrine.

COMPUTE CCC 52 = 0.

EXECUTE.

IF $((dsq 52f \ge 2) & (dsq 52s \ge 2)) CCC_52 = 1.$

EXECUTE.

COMPUTE CCC 53 = 0.

EXECUTE.

IF $((dsq_53f \ge 2) & (dsq_53s \ge 2)) CCC_53 = 1.$

EXECUTE.

COMPUTE CCC 54 = 0.

EXECUTE.

IF $((dsq_54f \ge 2) & (dsq_54s \ge 2)) CCC_54 = 1.$

EXECUTE.

COMPUTE CCC 55 = 0.

EXECUTE.

IF $((dsq_55f \ge 2) & (dsq_55s \ge 2)) CCC_55 = 1.$

EXECUTE.

COMPUTE CCC 56 = 0.

EXECUTE.

IF $((dsq 56f \ge 2) & (dsq 56s \ge 2))$ CCC 56 = 1.

EXECUTE.

COMPUTE CCC 57 = 0.

EXECUTE.

IF $((dsq 57f \ge 2) & (dsq 57s \ge 2))$ CCC 57 = 1.

EXECUTE.

COMPUTE CCC 58 = 0.

EXECUTE.

IF $((dsq 58f \ge 2) & (dsq 58s \ge 2))$ CCC 58 = 1.

EXECUTE.

COMPUTE CCC 59 = 0.

EXECUTE.

IF $((dsq 59f \ge 2) & (dsq 59s \ge 2))$ CCC 59 = 1.

EXECUTE.

COMPUTE CCC 60 = 0.

EXECUTE.

IF $((dsq 60f \ge 2) & (dsq 60s \ge 2))$ CCC 60 = 1.

EXECUTE.

COMPUTE CCC 61 = 0.

EXECUTE.

IF $((dsq 61f \ge 2) & (dsq 61s \ge 2))$ CCC 61 = 1.

EXECUTE.

COMPUTE CCC Neuroendo = 0.

EXECUTE.

IF(SUM(CCC 52, CCC 53, CCC 54, CCC 55, CCC 56, CCC 57, CCC 58, CCC 59,

CCC 60, CCC 61) >= 1) CCC Neuroendo = 1.

^{*}Immune*.

COMPUTE $CCC_62 = 0$.

EXECUTE.

IF $((dsq_62f \ge 2) & (dsq_62s \ge 2))$ CCC_62 = 1.

EXECUTE.

COMPUTE CCC 63 = 0.

EXECUTE.

IF $((dsq_63f \ge 2) & (dsq_63s \ge 2))$ CCC_63 = 1.

EXECUTE.

COMPUTE CCC 64 = 0.

EXECUTE.

IF $((dsq 64f \ge 2) & (dsq 64s \ge 2))$ CCC 64 = 1.

EXECUTE.

COMPUTE CCC 65 = 0.

EXECUTE.

IF $((dsq 65f \ge 2) & (dsq 65s \ge 2))$ CCC 65 = 1.

EXECUTE.

COMPUTE CCC 66 = 0.

EXECUTE.

IF $((dsq 66f \ge 2) & (dsq 66s \ge 2))$ CCC 66 = 1.

EXECUTE.

COMPUTE CCC Immune = 0.

EXECUTE.

IF(SUM(CCC_62, CCC_63, CCC_64, CCC_65, CCC_66) >= 1) CCC_Immune = 1.

EXECUTE.

Canadian ME/CFS Case Definition.

COMPUTE CCC ANI2 = 0.

EXECUTE.

IF(SUM(CCC Auto, CCC Neuroendo, CCC Immune) >= 2) CCC ANI2 = 1.

EXECUTE.

COMPUTE CCC = 0.

EXECUTE.

IF(SUM(CCC_SR, CCC_Fatigue, CCC_PEM, CCC_Sleep, CCC_Pain, CCC_Neurocog,

CCC ANI2 = 7 CCC = 1.

EXECUTE.

VALUE LABELS

CCC

0 'Does Not Meet Canadian MECFS Criteria'

1 'Meets Canadian MECFS Criteria'.

***************************** *DSO-1*. *International Consensus Criteria for ME (ME-ICC; Carruthers et al., 2011)*. *********************** **50 Percent Reduction in Activity**. COMPUTE MEICC SR = 0. EXECUTE. IF(dsq 97 = 1) MEICC SR = 1. EXECUTE. **PENE**. COMPUTE MEICC 14 = 0. EXECUTE. IF $((dsq 14f \ge 2) & (dsq 14s \ge 2))$ MEICC 14 = 1. EXECUTE. COMPUTE MEICC 15 = 0. EXECUTE. IF $((dsq 15f \ge 2) & (dsq 15s \ge 2))$ MEICC 15 = 1. EXECUTE. COMPUTE MEICC 16 = 0. EXECUTE. IF $((dsq \ 16f \ge 2) \& (dsq \ 16s \ge 2))$ MEICC 16 = 1. EXECUTE. COMPUTE MEICC 17 = 0. EXECUTE. IF $((dsq 17f \ge 2) & (dsq 17s \ge 2))$ MEICC 17 = 1. EXECUTE. COMPUTE MEICC 18 = 0. EXECUTE. IF $((dsq 18f \ge 2) & (dsq 18s \ge 2))$ MEICC 18 = 1. EXECUTE. COMPUTE MEICC PENE = 0.

EXECUTE.

IF(SUM(MEICC 14, MEICC 15, MEICC 16, MEICC 17, MEICC 18) >= 1) MEICC PENE = 1.

EXECUTE.

COMPUTE MEICC 36 = 0.

^{**}Neurological Impairments**.

^{*}Neurocognitive*.

EXECUTE.

IF ((dsq_36f>= 2) & (dsq_36s>= 2)) MEICC_36 = 1. EXECUTE.

COMPUTE MEICC 37 = 0.

EXECUTE.

IF ((dsq_37f>= 2) & (dsq_37s>= 2)) MEICC_37 = 1. EXECUTE.

COMPUTE MEICC 38 = 0.

EXECUTE.

IF ((dsq_38f>= 2) & (dsq_38s>= 2)) MEICC_38 = 1. EXECUTE.

COMPUTE MEICC_39 = 0.

EXECUTE.

IF $((dsq_39f \ge 2) & (dsq_39s \ge 2))$ MEICC_39 = 1. EXECUTE.

COMPUTE MEICC 40 = 0.

EXECUTE.

IF ((dsq_40f>= 2) & (dsq_40s>= 2)) MEICC_40 = 1. EXECUTE.

COMPUTE MEICC 41 = 0.

EXECUTE.

IF $((dsq_41f >= 2) & (dsq_41s >= 2))$ MEICC_41 = 1. EXECUTE.

COMPUTE MEICC_42 = 0.

EXECUTE.

IF $((dsq_42f >= 2) & (dsq_42s >= 2))$ MEICC_42 = 1. EXECUTE.

COMPUTE MEICC 43 = 0.

EXECUTE.

IF $((dsq_43f >= 2) & (dsq_43s >= 2))$ MEICC_43 = 1. EXECUTE.

COMPUTE MEICC 44 = 0.

EXECUTE.

IF ((dsq_44f>= 2) & (dsq_44s>= 2)) MEICC_44 = 1. EXECUTE.

COMPUTE MEICC Cognitive = 0.

EXECUTE.

IF(SUM(MEICC_36, MEICC_37, MEICC_38, MEICC_39, MEICC_40, MEICC_41, MEICC_42, MEICC_43, MEICC_44) >= 1) MEICC_Cognitive = 1. EXECUTE.

Pain.

COMPUTE MEICC 25 = 0.

EXECUTE.

IF $((dsq_25f \ge 2) & (dsq_25s \ge 2))$ MEICC_25 = 1.

EXECUTE.

COMPUTE MEICC 26 = 0.

EXECUTE.

IF $((dsq \ 26f \ge 2) \& (dsq \ 26s \ge 2))$ MEICC 26 = 1.

EXECUTE.

COMPUTE MEICC 27 = 0.

EXECUTE.

IF $((dsq 27f \ge 2) & (dsq 27s \ge 2))$ MEICC 27 = 1.

EXECUTE.

COMPUTE MEICC 28 = 0.

EXECUTE.

IF $((dsq \ 28f \ge 2) \& (dsq \ 28s \ge 2))$ MEICC 28 = 1.

EXECUTE.

COMPUTE MEICC 31 = 0.

EXECUTE.

IF $((dsq 31f \ge 2) & (dsq 31s \ge 2))$ MEICC 31 = 1.

EXECUTE.

COMPUTE MEICC Pain = 0.

EXECUTE.

IF(SUM(MEICC_25, MEICC_26, MEICC_27, MEICC_28, MEICC_31) >= 1) MEICC_Pain =

1

EXECUTE.

Sleep.

COMPUTE MEICC 19 = 0.

EXECUTE.

IF $((dsq 19f \ge 2) & (dsq 19s \ge 2))$ MEICC 19 = 1.

EXECUTE.

COMPUTE MEICC 20 = 0.

EXECUTE.

IF $((dsq \ 20f \ge 2) \& (dsq \ 20s \ge 2))$ MEICC 20 = 1.

EXECUTE.

COMPUTE MEICC 21 = 0.

EXECUTE.

IF $((dsq_21f \ge 2) & (dsq_21s \ge 2))$ MEICC_21 = 1.

COMPUTE MEICC 22 = 0.

EXECUTE.

IF $((dsq 22f \ge 2) & (dsq 22s \ge 2))$ MEICC 22 = 1.

EXECUTE.

COMPUTE MEICC 23 = 0.

EXECUTE.

IF $((dsq_23f \ge 2) & (dsq_23s \ge 2))$ MEICC_23 = 1.

EXECUTE.

COMPUTE MEICC 24 = 0.

EXECUTE.

IF $((dsq_24f >= 2) & (dsq_24s >= 2))$ MEICC_24 = 1.

EXECUTE.

COMPUTE MEICC Sleep = 0.

EXECUTE.

IF(SUM(MEICC_19, MEICC_20, MEICC_21, MEICC_22, MEICC_23, MEICC_24) >= 1)

 $MEICC_Sleep = 1.$

EXECUTE.

Neurosensory.

COMPUTE MEICC 32 = 0.

EXECUTE.

IF $((dsq 32f \ge 2) & (dsq 32s \ge 2))$ MEICC 32 = 1.

EXECUTE.

COMPUTE MEICC 33 = 0.

EXECUTE.

IF $((dsq 33f \ge 2) & (dsq 33s \ge 2))$ MEICC 33 = 1.

EXECUTE.

COMPUTE MEICC 34 = 0.

EXECUTE.

IF $((dsq 34f \ge 2) & (dsq 34s \ge 2))$ MEICC 34 = 1.

EXECUTE.

COMPUTE MEICC_35 = 0.

EXECUTE.

IF $((dsq 35f \ge 2) & (dsq 35s \ge 2))$ MEICC 35 = 1.

EXECUTE.

COMPUTE MEICC 48 = 0.

EXECUTE.

IF $((dsq \ 48f \ge 2) \& (dsq \ 48s \ge 2))$ MEICC 48 = 1.

EXECUTE.

COMPUTE MEICC Sensory = 0.

IF(SUM(MEICC 32, MEICC 33, MEICC 34, MEICC 35, MEICC 48) >= 1) MEICC Sensory = 1.EXECUTE. **Neurological Impairments**. COMPUTE MEICC Neuro = 0. EXECUTE. IF(SUM(MEICC Cognitive, MEICC Pain, MEICC Sleep, MEICC Sensory) >= 3) MEICC Neuro = 1. EXECUTE. **Immune, Gastrointestinal, Genitourinary Impairments**. *Flu*. COMPUTE MEICC 62 = 0. EXECUTE. IF $((dsq 62f \ge 2) & (dsq 62s \ge 2))$ MEICC 62 = 1. EXECUTE. COMPUTE MEICC 63 = 0. EXECUTE. IF $((dsq 63f \ge 2) & (dsq 63s \ge 2))$ MEICC 63 = 1. EXECUTE. COMPUTE MEICC 64 = 0. EXECUTE. IF $((dsq 64f \ge 2) & (dsq 64s \ge 2))$ MEICC 64 = 1. EXECUTE. COMPUTE MEICC 65 = 0. EXECUTE. IF $((dsq 65f \ge 2) & (dsq 65s \ge 2))$ MEICC 65 = 1. EXECUTE. COMPUTE MEICC Flu = 0. EXECUTE. IF(SUM(MEICC 62, MEICC 63, MEICC 64, MEICC 65) \geq 1) MEICC Flu = 1. EXECUTE. *Gastrointestinal*. COMPUTE MEICC 29 = 0. EXECUTE. IF $((dsq 29f \ge 2) & (dsq 29s \ge 2))$ MEICC 29 = 1. EXECUTE.

COMPUTE MEICC 30 = 0.

EXECUTE.

IF $((dsq \ 30f \ge 2) \& (dsq \ 30s \ge 2))$ MEICC 30 = 1.

EXECUTE.

COMPUTE MEICC 46 = 0.

EXECUTE.

IF $((dsq_46f \ge 2) & (dsq_46s \ge 2))$ MEICC_46 = 1.

EXECUTE.

COMPUTE MEICC 47 = 0.

EXECUTE.

IF $((dsq 47f \ge 2) & (dsq 47s \ge 2))$ MEICC 47 = 1.

EXECUTE.

COMPUTE MEICC Gastro = 0.

EXECUTE.

IF(SUM(MEICC 29, MEICC 30, MEICC 46, MEICC 47) >= 1) MEICC Gastro = 1.

EXECUTE.

Genitourinary.

COMPUTE MEICC Urinary = 0.

EXECUTE.

IF $((dsq \ 45f \ge 2) \& (dsq \ 45s \ge 2))$ MEICC Urinary = 1.

EXECUTE.

Sensitivities.

COMPUTE MEICC 61 = 0.

EXECUTE.

IF $((dsq 61f \ge 2) & (dsq 61s \ge 2))$ MEICC 61 = 1.

EXECUTE.

COMPUTE MEICC 66 = 0.

EXECUTE.

IF $((dsq 66f \ge 2) & (dsq 66s \ge 2))$ MEICC 66 = 1.

EXECUTE.

COMPUTE MEICC Sensitivity = 0.

EXECUTE.

IF(SUM(MEICC_61, MEICC_66) >= 1) MEICC_Sensitivity = 1.

EXECUTE.

Virus Susceptibility.

COMPUTE MEICC Viral = 0.

EXECUTE.

IF(dsq 98 = 1) MEICC Viral = 1.

```
**Immune, Gastrointestinal, Genitourinary Impairments**.

COMPUTE MEICC_IGG = 0.

EXECUTE.

IF(SUM(MEICC_Flu, MEICC_Gastro, MEICC_Urinary, MEICC_Sensitivity, MEICC_Viral)
>= 3) MEICC_IGG = 1.
```

Energy Metabolism, Ion Transport Impairments.

Cardiovascular

COMPUTE MEICC 50 = 0.

EXECUTE.

EXECUTE.

IF $((dsq_50f \ge 2) & (dsq_50s \ge 2))$ MEICC_50 = 1.

EXECUTE.

COMPUTE MEICC 51 = 0.

EXECUTE.

IF $((dsq 51f \ge 2) & (dsq 51s \ge 2))$ MEICC 51 = 1.

EXECUTE.

COMPUTE MEICC Cardio = 0.

EXECUTE.

IF(SUM(MEICC 50, MEICC 51) >= 1) MEICC Cardio = 1.

EXECUTE.

Respiratory.

COMPUTE MEICC Resp = 0.

EXECUTE.

IF($(dsq 49f \ge 2) & (dsq 49s \ge 2)$) MEICC Resp = 1.

EXECUTE.

Thermostatic Ability.

COMPUTE MEICC 54 = 0.

EXECUTE.

IF $((dsq 54f \ge 2) & (dsq 54s \ge 2))$ MEICC 54 = 1.

EXECUTE.

COMPUTE MEICC 55 = 0.

EXECUTE.

IF $((dsq_55f \ge 2) & (dsq_55s \ge 2))$ MEICC_55 = 1.

EXECUTE.

COMPUTE MEICC 56 = 0.

EXECUTE.

IF $((dsq 56f \ge 2) & (dsq 56s \ge 2))$ MEICC 56 = 1.

EXECUTE.

COMPUTE MEICC 57 = 0.

```
EXECUTE.
IF ((dsq 57f \ge 2) & (dsq 57s \ge 2)) MEICC 57 = 1.
EXECUTE.
COMPUTE MEICC 58 = 0.
EXECUTE.
IF ((dsq 58f \ge 2) & (dsq 58s \ge 2)) MEICC 58 = 1.
EXECUTE.
COMPUTE MEICC 59 = 0.
EXECUTE.
IF ((dsq 59f \ge 2) & (dsq 59s \ge 2)) MEICC 59 = 1.
EXECUTE.
COMPUTE MEICC 60 = 0.
EXECUTE.
IF ((dsq 60f \ge 2) & (dsq 60s \ge 2)) MEICC 60 = 1.
EXECUTE.
COMPUTE MEICC Thermo = 0.
EXECUTE.
IF(SUM(MEICC 54, MEICC 55, MEICC 56, MEICC_57, MEICC_58, MEICC_59,
MEICC 60) >= 1) MEICC Thermo = 1.
EXECUTE.
*Temperature Intolerance*.
COMPUTE MEICC_Temp = 0.
EXECUTE.
IF(dsq 99 = 1) MEICC Temp = 1.
EXECUTE.
**Immune, Gastrointestinal, Genitourinary Impairments**.
COMPUTE MEICC Energy = 0.
EXECUTE.
IF(SUM(MEICC Cardio, MEICC Resp, MEICC Thermo, MEICC Temp) >= 1)
MEICC Energy = 1.
EXECUTE.
***ME-ICC Case Definition***.
COMPUTE MEICC = 0.
EXECUTE.
IF(SUM(MEICC SR, MEICC PENE, MEICC Neuro, MEICC IGG, MEICC Energy) = 5)
MEICC = 1.
EXECUTE.
```

VALUE LABELS MEICC 0 'Does Not Meet ME-ICC' 1 'Meets ME-ICC'. EXECUTE. ***********************

DSQ-1.

Institute of Medicine Criteria (IOM, 2015).

```
***Substantial Reduction in Functioning Criteria, SF-36***.
```

COMPUTE IOM RP = 0.

EXECUTE.

IF (RolePhysical ≤ 50) IOM RP = 1.

EXECUTE.

COMPUTE IOM SF = 0.

EXECUTE.

IF (SocialFunctioning \leq 62.5) IOM SF = 1.

EXECUTE.

COMPUTE IOM V = 0.

EXECUTE.

IF (Vitality ≤ 35) IOM V = 1.

EXECUTE.

COMPUTE IOM SR=0.

EXECUTE.

IF (SUM(IOM RP, IOM SF, IOM V) \geq 2) IOM SR = 1.

EXECUTE.

DSQ-1 Symptom Scoring.

Fatigue, Not Lifelong, Not Result of Exertion.

COMPUTE IOM Six = 0.

EXECUTE.

IF ((dsq 69 = 2) | (dsq 69 = 3) | (dsq 69 = 4) | (dsq 69 = 5)) IOM Six = 1.

EXECUTE.

COMPUTE IOM Life = 0.

EXECUTE.

IF ((dsq 67 = 1) & (dsq 69 = 5) & (dsq 77 = 7)) IOM Life = 1.

EXECUTE.

COMPUTE IOM Exert = 0.

EXECUTE.

 $IF((SUM(dsq 89a, dsq 89d) \ge 60)) IOM Exert = 1.$

^{***}To score the SF-36, use scoring rules found here:

^{***}https://www.rand.org/health/surveys tools/mos/36-item-short-form/scoring.html***.

^{***}Variable names are equivalent to SF-36 Subscale Names***.

EXECUTE. COMPUTE IOM Fatigue = 0. EXECUTE. $IF((IOM Six = 1) & (IOM Life = 0) & (IOM Exert = 0)) IOM_Fatigue = 1.$ EXECUTE. *Post-Exertional Malaise*. COMPUTE IOM 14 = 0. EXECUTE. IF $((dsq 14f \ge 2) & (dsq 14s \ge 2))$ IOM 14 = 1. EXECUTE. COMPUTE IOM 15 = 0. EXECUTE. IF $((dsq 15f \ge 2) & (dsq 15s \ge 2))$ IOM 15 = 1. EXECUTE. COMPUTE IOM 16 = 0. EXECUTE. IF $((dsq \ 16f \ge 2) \& (dsq \ 16s \ge 2))$ IOM 16 = 1. EXECUTE. COMPUTE IOM 17 = 0. EXECUTE. IF $((dsq 17f \ge 2) & (dsq 17s \ge 2))$ IOM 17 = 1. EXECUTE. COMPUTE IOM 18 = 0. EXECUTE. IF $((dsq 18f \ge 2) & (dsq 18s \ge 2))$ IOM 18 = 1. EXECUTE. COMPUTE IOM PEM = 0. EXECUTE. IF(SUM(IOM 14, IOM 15, IOM 16, IOM 17, IOM 18) >= 1) IOM PEM = 1.EXECUTE. *Unrefreshing Sleep*. COMPUTE IOM 19 = 0. EXECUTE. IF $((dsq 19f \ge 2) & (dsq 19s \ge 2))$ IOM 19 = 1. EXECUTE. COMPUTE IOM 20 = 0. EXECUTE.

IF $((dsq \ 20f \ge 2) \& (dsq \ 20s \ge 2))$ IOM 20 = 1.

COMPUTE IOM 21 = 0.

EXECUTE.

IF $((dsq_21f \ge 2) & (dsq_21s \ge 2)) IOM_21 = 1.$

EXECUTE.

COMPUTE IOM 22 = 0.

EXECUTE.

IF $((dsq 22f \ge 2) & (dsq_22s \ge 2)) IOM_22 = 1.$

EXECUTE.

COMPUTE IOM 24 = 0.

EXECUTE.

IF $((dsq 24f \ge 2) & (dsq 24s \ge 2))$ IOM 24 = 1.

EXECUTE.

COMPUTE IOM Sleep = 0.

EXECUTE.

IF(SUM(IOM 19, IOM 20, IOM 21, IOM 22, IOM 24) >= 1) IOM Sleep = 1.

EXECUTE.

Cognitive Impairment.

COMPUTE IOM 36 = 0.

EXECUTE.

IF $((dsq 36f \ge 2) & (dsq 36s \ge 2))$ IOM 36 = 1.

EXECUTE.

COMPUTE IOM 37 = 0.

EXECUTE.

IF $((dsq 37f \ge 2) & (dsq_37s \ge 2)) IOM_37 = 1.$

EXECUTE.

COMPUTE IOM 38 = 0.

EXECUTE.

IF $((dsq 38f \ge 2) & (dsq 38s \ge 2))$ IOM 38 = 1.

EXECUTE.

COMPUTE IOM 39 = 0.

EXECUTE.

IF $((dsq 39f \ge 2) & (dsq 39s \ge 2))$ IOM 39 = 1.

EXECUTE.

COMPUTE IOM 40 = 0.

EXECUTE.

IF $((dsq \ 40f \ge 2) \& (dsq \ 40s \ge 2))$ IOM 40 = 1.

EXECUTE.

COMPUTE IOM 43 = 0.

IF $((dsq \ 43f \ge 2) \& (dsq \ 43s \ge 2))$ IOM 43 = 1. EXECUTE. COMPUTE IOM 44 = 0. EXECUTE. IF $((dsq \ 44f \ge 2) \& (dsq \ 44s \ge 2))$ IOM 44 = 1. EXECUTE. COMPUTE IOM Cognitive = 0. EXECUTE. IF(SUM(IOM 36, IOM 37, IOM 38, IOM 39, IOM 40, IOM 43, IOM 44) >= 1) IOM Cognitive = 1. EXECUTE. *Orthostatic Intolerance*. COMPUTE IOM 48 = 0. EXECUTE. IF $((dsq \ 48f \ge 2) \& (dsq \ 48s \ge 2))$ IOM 48 = 1. EXECUTE. COMPUTE IOM 49 = 0. EXECUTE. IF $((dsq \ 49f \ge 2) \& (dsq \ 49s \ge 2))$ IOM 49 = 1. EXECUTE. COMPUTE IOM 50 = 0. EXECUTE. IF $((dsq 50f \ge 2) & (dsq 50s \ge 2))$ IOM 50 = 1. EXECUTE. COMPUTE IOM 51 = 0. EXECUTE. IF $((dsq 51f \ge 2) & (dsq 51s \ge 2))$ IOM 51 = 1. EXECUTE. COMPUTE IOM OI = 0. EXECUTE. IF(SUM(IOM 48, IOM 49, IOM 50, IOM 51) \geq 1) IOM OI = 1. EXECUTE. ***IOM Case Definition***. COMPUTE IOM = 0. EXECUTE. IF((SUM(IOM SR, IOM Fatigue, IOM PEM, IOM Sleep) = 4) & (SUM(IOM Cognitive, IOM OI) >= 1)) IOM = 1.

VALUE LABELS

IOM 0 'Does Not Meet IOM Criteria' 1 'Meets IOM Criteria'. EXECUTE.

DePaul Symptom Questionnaire (DSQ-1)

1.	What is your height?
2.	What is your weight?
3.	What is your date of birth?
4.	. What is your gender?
5.	To which of the following race(s) do you belong?
	☐ Black, African-American
	□ White
	☐ American Indian or Alaska Native
	☐ Asian or Pacific Islander
	☐ Other race (<i>Please specify</i>)
6.	Are you of Latino or Hispanic origin?
	□ Yes □ No
7.	What is your current marital status?
	☐ Married or living with partner
	☐ Separated
	□ Widowed
	□ Divorced
	☐ Never married
8.	Do you have any children?
	\square Yes \square No (Skip to Question 9)
	8a. How many children do you have?
	8b. How many of your children are under 18 years old?

9. How many people live in your home?
10. What grade or degree have you completed in school?
☐ Less than high school
☐ Some high school
☐ High school degree or GED
☐ Partial college (at least one year) or specialized training
☐ Standard college degree
☐ Graduate professional degree including masters and doctorate
11. What is your current work status? (Check all that apply)
☐ On disability
□ Student
☐ Homemaker
☐ Working part-time
☐ Working full-time
11a. If you are on disability, for what condition do you receive disability compensation?
Please Specify
12. What is your current occupation?
Current
12a. If you are currently not working, what was your most recent occupation?
Most Recent

For the following questions (13-66), we would like to know **how often you have had each symptom** and **how much each symptom has bothered you over the last 6 months**. For each symptom please circle **one number for frequency and one number for severity**. Please fill the chart out from left to right.

		F	requency	<u>'</u> :			Å	Severity:			
			e past 6 ou had th					e <u>past 6</u> is sympto you?			
Symptoms		For each symptom listed below, circle a number from:					For each symptom listed below, circle a number from:				
		0 = none of the time 0 = symptom not present									
	1 = a little of the time 1 = mild										
	2 = abo	out half	the time			2 = mo	derate				
	3 = most of the time $3 = severe$										
	4 = all	of the ti	me			4 = ver	y sever	e			
13) Fatigue/extreme tiredness	0	1	2	3	4	0	1	2	3	4	
14) Dead, heavy feeling after starting to exercise	0	1	2	3	4	0	1	2	3	4	
15) Next day soreness or fatigue after non-strenuous, everyday activities	0	1	2	3	4	0	1	2	3	4	
16) Mentally tired after the slightest effort	0	1	2	3	4	0	1	2	3	4	
17) Minimum exercise makes you physically tired	0	1	2	3	4	0	1	2	3	4	
18) Physically drained or sick after mild activity	0	1	2	3	4	0	1	2	3	4	
19) Feeling unrefreshed after you wake up in the morning	0	1	2	3	4	0	1	2	3	4	
20) Need to nap daily	0	1	2	3	4	0	1	2	3	4	
21) Problems falling asleep	0	1	2	3	4	0	1	2	3	4	
22) Problems staying asleep	0	1	2	3	4	0	1	2	3	4	
23) Waking up early in the morning (e.g. 3am)	0	1	2	3	4	0	1	2	3	4	
24) Sleep all day and stay awake all night	0	1	2	3	4	0	1	2	3	4	
25) Pain or aching in your muscles	0	1	2	3	4	0	1	2	3	4	
26) Pain/stiffness/tenderness in more than one joint without swelling or redness	0	1	2	3	4	0	1	2	3	4	
27) Eye pain	0	1	2	3	4	0	1	2	3	4	

		Fi	requency	·:				Severity:			
Symptoms		Throughout the past 6 months , how often have you had this symptom?					Throughout the <u>past 6 months</u> , how <u>much</u> has this symptom bothered you?				
		For each symptom listed below, circle a number from:					For each symptom listed below, circle a number from:				
		ne of the	time			0 = symptom not present					
		1 = a little of the time									
	2 = ab	out half	the time	:		2 = mo	derate				
	3 = mc	ost of the	time			3= sev	ere				
	4 = all	of the ti	me			4 = ver	y sever	e			
28) Chest pain	0	1	2	3	4	0	1	2	3	4	
29) Bloating	0	1	2	3	4	0	1	2	3	4	
30) Abdomen/stomach pain	0	1	2	3	4	0	1	2	3	4	
31) Headaches	0	1	2	3	4	0	1	2	3	4	
32) Muscle twitches	0	1	2	3	4	0	1	2	3	4	
33) Muscle weakness	0	1	2	3	4	0	1	2	3	4	
34) Sensitivity to noise	0	1	2	3	4	0	1	2	3	4	
35) Sensitivity to bright lights	0	1	2	3	4	0	1	2	3	4	
36) Problems remembering things	0	1	2	3	4	0	1	2	3	4	
37) Difficulty paying attention for a long period of time	0	1	2	3	4	0	1	2	3	4	
38) Difficulty finding the right word to say or expressing thoughts	0	1	2	3	4	0	1	2	3	4	
39) Difficulty understanding things	0	1	2	3	4	0	1	2	3	4	
40) Only able to focus on one thing at a time	0	1	2	3	4	0	1	2	3	4	
41) Unable to focus vision and/or attention	0	1	2	3	4	0	1	2	3	4	
42) Loss of depth perception	0	1	2	3	4	0	1	2	3	4	
43) Slowness of thought	0	1	2	3	4	0	1	2	3	4	
44) Absent-mindedness or forgetfulness	0	1	2	3	4	0	1	2	3	4	
45) Bladder problems	0	1	2	3	4	0	1	2	3	4	
46) Irritable bowel problems	0	1	2	3	4	0	1	2	3	4	

	1	F	requency	·:				Severity:			
	Throughout the past 6 months , how often have you had this symptom?					Throughout the <u>past 6 months</u> , how <u>much</u> has this symptom bothered you?					
Symptoms		For each symptom listed below, circle a number from:					For each symptom listed below, circle a number from:				
		0 = none of the time 0 = symptom not present									
		1 = a little of the time 1 = mild									
	2 = about half the time 2 = moderate										
	$3 = m_0$	st of the	time			3= seve	ere				
	4 = all	of the ti	me			4 = ver	y sever	e			
47) Nausea	0	1	2	3	4	0	1	2	3	4	
48) Feeling unsteady on your feet, like you might fall	0	1	2	3	4	0	1	2	3	4	
49) Shortness of breath or trouble catching your breath	0	1	2	3	4	0	1	2	3	4	
50) Dizziness or fainting	0	1	2	3	4	0	1	2	3	4	
51) Irregular heart beats	0	1	2	3	4	0	1	2	3	4	
52) Losing or gaining weight without trying	0	1	2	3	4	0	1	2	3	4	
53) No appetite	0	1	2	3	4	0	1	2	3	4	
54) Sweating hands	0	1	2	3	4	0	1	2	3	4	
55) Night sweats	0	1	2	3	4	0	1	2	3	4	
56) Cold limbs (e.g. arms, legs, hands)	0	1	2	3	4	0	1	2	3	4	
57) Feeling chills or shivers	0	1	2	3	4	0	1	2	3	4	
58) Feeling hot or cold for no reason	0	1	2	3	4	0	1	2	3	4	
59) Feeling like you have a high temperature	0	1	2	3	4	0	1	2	3	4	
60) Feeling like you have a low temperature	0	1	2	3	4	0	1	2	3	4	
61) Alcohol intolerance	0	1	2	3	4	0	1	2	3	4	
62) Sore throat	0	1	2	3	4	0	1	2	3	4	
63) Tender/sore lymph nodes	0	1	2	3	4	0	1	2	3	4	
64) Fever	0	1	2	3	4	0	1	2	3	4	
65) Flu-like symptoms	0	1	2	3	4	0	1	2	3	4	
66) Some smells, foods, medications, or chemicals make you feel sick	0	1	2	3	4	0	1	2	3	4	

67	earliest memor	ries as a child?	tent or recurring fatigue/energy problems , even back to your (By persistent or recurring, we mean that the fatigue/energy g and constant, but sometimes there are good periods and bad
	□ Yes	□ No	□ Not having a problem with fatigue/energy
68	•	O O.	elated illness began, do your headaches either happen more vere, or are they in a different place or spot?
	□ Yes	\square No	□ Not having a problem with fatigue/energy
69	. How long ago	did your probl	lem with fatigue/energy begin?
	☐ Less that	n 6 months	
	□ 6-12 mo	nths	
	□ 1-2 years	S	
	□ Longer t	han 2 years	
	☐ Had prol	olem with fatig	gue/energy since childhood or adolescence
	□ Not havi	ng a problem	with fatigue/energy
70	. Have you been	diagnosed wi	th Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?
	□ Yes	\square No	
	70a. If yes, wha	t year were yo	ou diagnosed?
	70b. Do you cu Encephalor	•	diagnosis of Chronic Fatigue Syndrome or Myalgic
	□ Yes	\square No	
	70c. Who diagn	osed you with	Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?
	☐ Medical	Doctor \square A	Alternative Practitioner
		of your family ncephalomyel	members been diagnosed with Chronic Fatigue Syndrome or itis?
	□ Yes	\sqcap No	

If yes, please list their relation to you and current age
71. Did you experience any of the following symptoms regularly and repeatedly in the month and years <u>before</u> your fatigue/energy problems began?
☐ Sore throat
☐ Tender/sore lymph nodes
☐ Unrefreshing sleep
☐ Impaired memory and concentration
☐ Prolonged fatigue following physical or mental exertion
☐ Muscle pain
☐ Headaches
☐ Joint Pain
□ Not having a problem with fatigue/energy
72. If you rest, does your problem with fatigue/energy go away? (Check one)
□ Entirely
□ Partially
☐ My fatigue/energy problem is not improved by rest (Skip to Question 73)
☐ I am not having a problem with fatigue/energy (Skip to Question 73)
72a. How long do you have to rest for your problem with fatigue/energy to entirely or partially go away?
\Box less than 30 minutes \Box 30 to 59 minutes \Box 1-2 hours \Box more than 2 hours
73. If you were to become exhausted after actively participating in extracurricular activities, sports, or outings with friends, would you recover within an hour or two after the activity ended?
\Box Yes \Box No
74. Do you reduce your activity level to avoid experiencing problems with fatigue/energy ?
☐ Yes ☐ No ☐ Not having a problem with fatigue/energy

75. Do you experminimal phys			r fatigue/energy 1	related illness after engaging in
$\Box Yes$	□ No	□ Not having	g a problem with	fatigue/energy
75a. Do you e mental ef		a worsening of	your fatigue/ene r	rgy related illness after engaging in
□ Yes	\square No			
75b. If you fee	el worse af	ter activities, ho	ow long does this	last? (Check one)
□ 1 hour	or less	□ 2-3 Hrs	□ 4-10 Hrs	□ 11-13 Hrs
□ 14-23	Hrs	☐ More than 24	Hrs (Please spec	ify)
76. Are you curre	ently engag	ging in any forn	n of exercise?	
□ Yes (S	kip to Ques	stion 77)	□ No	
76a. If you do with)	not exerci	se, why aren't y	you exercising? (Check all boxes that you agree
□ Not int	terested			
□ No tim	ie			
□ Would	like to but	t cannot because	e of problems with	n fatigue/energy
	t because e	exercise makes s	symptoms worse	
77. Over what pe	eriod of tim	ne did your fati ş	gue/energy relate	ed illness, develop? (Check one)
□ Within	24 hours			
□ Over 1	week			
□ Over 1	month			
□ Over 2	-6 months			
□ Over 7	-12 month	S		
□ Over 1	-2 years			
□ Over 3	or more y	ears		
□ I am no	ot ill			

78. How would you describe the course of your fatigue/energy related illness? (Check one)
☐ Constantly getting worse
☐ Constantly improving
☐ Persisting (no change)
☐ Relapsing & remitting (having "good" periods with no symptoms & "bad" periods)
☐ Fluctuating (symptoms periodically get better and get worse, but never disappear completely)
□ No Symptoms/I am not ill
79. Which statement best describes your fatigue/energy related illness during the <u>last 6</u> <u>months</u> ? (Check one)
\square I am not able to work or do anything, and I am
bedridden.
$\hfill I$ can walk around the house, but I cannot do light housework.
☐ I can do light housework, but I cannot work part-time.
\square I can only work part-time at work or on some family responsibilities.
☐ I can work full time, but I have no energy left for anything else.
☐ I can work full time and finish some family responsibilities but I have no energy left for anything else.
\Box I can do all work or family responsibilities without any problems with my energy.
80. Did your fatigue/energy related illness start after you experienced any of the following? (Check one or more and please specify)
☐ An infectious illness
☐ An accident
☐ A trip or vacation
☐ An immunization (shot at doctor's office)
□ Surgery
☐ Severe stress (bad or unhappy event(s))
□ Other
□ I am not ill

problem		isulted a medical doctor or health professional about your laugue/energy
	Yes	□ No (Skip to Question 83)
82. Do you	u currently	have a medical doctor overseeing your fatigue/energy problem?
	Yes	\square No
83. Do you	ı have any	medical illness (es) that might be causing your symptoms?
	Yes	□ No (Skip to Question 84)
83a. W	hat medica	l illnesses do you have?
I11	ness name(s) and year it began:
_		
83b. Fe	or which of	these conditions are you currently receiving treatment?
_		
_		
84. Are yo	ou currently	taking any medications (over the counter or prescription)?
	Yes	No (Skip to Question 86)
84a. V	What medic	ations are you taking?
85. Do you	ı think any	medication(s) is (are) causing your problem with fatigue/energy ?
•	•	No (Skip to Question 86)
	I do not hay	re a problem with fatigue/energy (Skip to Ouestion 86)

85a. Please sp	becify which medications:
•	er been diagnosed and/or treated for any of the following: (Check all that rite year (s) experienced, years treated, and medication (if applicable)
□ Major o	depression_
□ Major o	depression with melancholic or psychotic features
☐ Bipolar	disorder (Manic-depression)
☐ Anxiet	y
□ Schizo _j	phrenia
	disorder
☐ Substar	nce abuse
	le chemical sensitivities
□ Fibrom	yalgia
□ Allergi	es
□ Other (Please specify)
□ No dia	gnosis/treatment
37. What do you	think is the cause of your problem with fatigue/energy? (Check one)
☐ Definit	ely physical
☐ Mainly	physical
□ Equally	physical and psychological
☐ Mainly	psychological
☐ Definit	ely psychological
□ No pro	blem with fatigue/energy
•	anything specific in your personal life or environment accounts for your fatigue/energy?
□ Yes	□ No (Skip to Question 89)
□ I do no	t have a problem with fatigue/energy (<i>Skip to Question 89</i>)

88a. Please specify:	
89. In the past 4 weeks , approximately how many h	nours per week have you spent doing:
Household related activities?	_hours per week
Social/Recreational related activities?	_hours per week
Family related activities?	_hours per week
Work related activities?	_hours per week
90. In the past 4 weeks , have you had to reduce the to your illness) on occupational, social or family problems with fatigue/energy ?	
☐ Yes ☐ No (Skip to Question 91)	□ Not having a problem with fatigue/energy
90a. Before your fatigue/energy related illnes used to spend on:	s, approximately how many hours did you
Household related activities?	_hours per week
Social/Recreational related activities?	_hours per week
Family related activities?	_hours per week
Work related activities?	_hours per week
91. Please rate the amount of energy you had availar where 1= no energy and 100 = your pre-illness energy energy and 100 = your pre-illness energy ener	gy level. (If you don't have a
fatigue/energy related illness, a score of 100 = ha work full time and complete your family respons	
92. Please rate the amount of energy you expended 100 where 1 = no energy and 100 = your pre-illness	
93. Please rate the amount of fatigue you had yeste no fatigue and 100 = severe fatigue	

-		ease rate the amount of energy you had available using a scale from 1 gy and 100 = your pre-illness energy level
-	-	ease rate the amount of energy you have expended (used) using a scale no energy and 100 = your pre-illness energy expended
-	-	ease rate the amount of fatigue you have had using a scale from 1 to and 100 = severe fatigue
	· ·	or problems with fatigue/energy, have your symptoms caused a 50% or activity level?
□ Yes	□ No	☐ Not having a problem with fatigue/energy
98. Do you e	experience fre	equent viral infections with prolonged recovery periods?
□ Yes		\square No
99. Are you	intolerant of	extremes of temperatures (when it is extremely hot or cold)?
□ Yes		\square No

To Measure Substantial Reduction Requirement in the Case Definitions MOS SURVEY (SF-36)

INSTRUCTIONS:

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: (*Please circle one*)

Excellent	1
Very good	2
Good	3
Fair	
Poor	5

2. <u>Compared to one year ago,</u> how would you rate your health in general now? (*Please circle one*)

Much better than one year ago	. 1
Somewhat better now than one year ago	
About the same as one year ago	. 3
Somewhat worse now than one year ago	. 4
Much worse now than one year ago	. 5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

<u>Activities</u>	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
Vigorous activities: running, lifting heavy objects, participating in strenuous	1	2	3
sports			
Moderate activities : moving a table, pushing a vacuum cleaner, bowling, playing golf	1	2	3
Lifting or carrying groceries	1	2	3
Climbing several flights of stairs	1	2	3
Climbing one flight of stairs	1	2	3
Bending, kneeling, or stooping	1	2	3
Walking more than a mile	1	2	3
Walking several blocks	1	2	3
Walking one block	1	2	3
Bathing or dressing yourself	1	2	3

4. During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities as a result of your **physical health**?

<u>Problems</u>	Yes	No
Cut down on the amount of time you spent on work or other activities	1	2
Accomplished less than you would like	1	2
Were limited in the kind of work or other activities	1	2
Had difficulty performing the work or other activities (For example, it took extra	1	2
effort)		

regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<u>Problems</u>	Yes	No
Cut down the amount of time you spent on work or other activities	1	2
Accomplished less than you would like	1	2
Didn't do work or other activities as carefully as usual	1	2

6.	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with
	your normal social activities with family, neighbors, or groups? (Please circle one)

Not at all	
Slightly	
Moderately	
Quite a bit	
Extremely	

7. How much bodily pain have you had during the **past 4 weeks**?

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very Severe	6

8. During the <u>past 4 weeks</u>, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	1
Slightly	2
Moderately	
Quite a bit	
Extremely	5

9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time <u>during the past 4 weeks</u>-

<u>Questions</u>	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
Did you feel full of pep?	1	2	3	4	5	6
Have you been a nervous person?	1	2	3	4	5	6
Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
Have you felt calm and peaceful?	1	2	3	4	5	6
Did you have a lot of energy?	1	2	3	4	5	6
Have you felt down-hearted and blue?	1	2	3	4	5	6
Did you feel worn out?	1	2	3	4	5	6
Have you been a happy person?	1	2	3	4	5	6
Did you feel tired?	1	2	3	4	5	6

10.	During the past 4 weeks, how much of the time has your physical health or
	emotional problems interfered with your social activities (like visiting with friends
	relatives, etc.)?

All of the time	1
-----------------	---

Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

11. How **TRUE** or **FALSE** is each of following statements for you?

<u>Statements</u>	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
I seem to get sick a little easier than other people	1	2	3	4	5
I am as healthy as anybody I know	1	2	3	4	5
I expect my health to get worse	1	2	3	4	5
My health is excellent	1	2	3	4	5