BPSU Severe CFS/ME Data Collection Form v4.0 31/01/2018
IRAS Project ID: 223838

BPSU ID: ☐☐ ☐☐☐☐ ☐☐

British Paediatric Surveillance Unit Study Severe Chronic Fatigue Syndrome/Myalgic Encephalitis

Data Collection Form

CONFIDENTIAL

Section A: Reporter Details

1.1 Date of completion of questionnaire: DD/MM/YYYY

1.2 Consultant responsible for case: ____________________

1.3 Hospital name: ____________________

1.4 Telephone number: ____________________ Email: ____________________

1.5 Has the patient been referred to/from another centre? Yes ☐ No ☐ Not known ☐

If yes: 1) please name centre: ____________________

2) please name consultant: ____________________

Section B: Case Details

2.1 NHS/CHI No: ☐☐☐ ☐☐☐ ☐☐☐☐

2.2 Hospital No: ☐☐☐☐☐☐☐☐☐☐

2.3 Sex: M ☐ F ☐ Date of birth: DD/MM/YYYY

2.4 Ethnicity*: ☐☐ Specify if any "Other" background

**Please choose the correct ethnicity code from Appendix A overleaf*

2.5 Partial postcode (first three letters) ☐☐☐

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Appendix A

Appendix A: Coding for Ethnic Group (ONS 2001 for UK / Ireland wide data collection)

		Ethnicity Code	
A	**White**	**1**	Any White background
B	**Mixed**	**2**	White and Black Caribbean
		3	White and Black African
		4	White and Asian
		5	Any Other Mixed background, *please write in **section***
C	**Asian or Asian British**	**6**	Indian
		7	Pakistani
		8	Bangladeshi
		9	Any Other Asian background, *please write in **section***
D	**Black or British Black**	**10**	Caribbean
		11	African
		12	Any Other African background, *please write in **section***
E	**Chinese or other ethnic group**	**13**	Chinese
		14	Any Other, *please write in **section***
F	**Unknown**	**15**	Ethnicity not known

Royston AP, *et al. Arch Dis Child* 2023; 108:230–235. doi: 10.1136/archdischild-2022-324319

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Section C: Presentation/Clinical features

Give best possible estimate

3.1 Date when fatigue (as reported by mother/chid or first recorded by medical team) DD/MM/YY

Date of diagnosis DD/MM/YY

3.2 Date when became housebound DD/MM/YY

3.3 Date of most recent medical assessment DD/MM/YY

3.4 **The fatigue:** *(Please tick)*

	Yes	No	Don't know
Is not lifelong (fatigue not noticeable from birth)	☐	☐	☐
Lasted 3 months or longer	☐	☐	☐
Not due to over exertion (for example sport)	☐	☐	☐
Not relieved by rest	☐	☐	☐
Is not because of other medical conditions	☐	☐	☐
Means child unable to leave the house without severe and prolonged after effect.	☐	☐	☐
Means child only leaves house occasionally (less than once a week)	☐	☐	☐
Causes significant reduction in ability to carry out activities of daily living (eating, drinking, preparing food, toileting, washing, walking)	☐	☐	☐

3.5 Does the child have the following symptoms?

	Yes	No	Don't know
Impaired memory or concentration	☐	☐	☐
Post-exertion malaise*	☐	☐	☐
Problems with sleep including un-refreshing sleep	☐	☐	☐
Muscle pain	☐	☐	☐
Pain in multiple joints	☐	☐	☐
Headaches of a new kind or greater severity	☐	☐	☐
Sore throat, frequent or recurring	☐	☐	☐
Tender lymph nodes (cervical or axillary)	☐	☐	☐

* physical or mental exertions bring on "extreme, prolonged exhaustion and sickness"

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Section D: Function

Give best possible estimate

4.1 What has the child's school attendance been over the last 6 weeks? (Please tick best estimate)

	Yes
No tuition (no home tuition or schooling)	☐
Home tuition	☐
Attending school or hospital school for less than one hour a week	☐
Attending school for more than one hour a week	☐
Don't know	☐

***if it has been the school holidays please use equivalent activity**

4.2 What is the child's current level of independence in activities of daily living?" (eating, drinking, preparing food, toileting, washing, walking)

	Yes
Requires help with all activities of daily living	☐
Requires some help with daily activities sometimes	☐
Able to do all daily activities over last 6 weeks	☐

Please provide further information:

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Section D: Investigations and Management

5.1 Are the following test results in the normal range based on your local lab ranges?

	Yes	No	Not done or don't know
full blood count,	☐	☐	☐
urea and electrolytes	☐	☐	☐
serum creatinine	☐	☐	☐
thyroid function	☐	☐	☐
erythrocyte sedimentation rate or plasma viscosity	☐	☐	☐
C-reactive protein	☐	☐	☐
random blood glucose	☐	☐	☐
screening blood tests for gluten sensitivity	☐	☐	☐
serum calcium	☐	☐	☐
creatine kinase	☐	☐	☐
serum ferritin	☐	☐	☐
liver function	☐	☐	☐
Urinalysis	☐	☐	☐

5.2 Has the child received any of the following? (please tick all that apply)

	Yes	No	Don't Know
Cognitive Behaviour Therapy	☐	☐	☐
Graded Exercise Therapy	☐	☐	☐
Activity Management	☐	☐	☐
Medication for symptoms	☐	☐	☐
Domiciliary assessment or treatment	☐	☐	☐
Treatment from CAMHS?	☐	☐	☐
Physiotherapy?	☐	☐	☐
Social services assessment/support?	☐	☐	☐

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Thank you for taking the time to complete the Questionnaire

Please print and return the completed form in the SAE to:

____

____

____

If you have any questions about the study please do not hesitate to contact the investigators by email or telephone:

Telephone: ____________________ Email: ______________________________

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