

**UK and Ireland Childhood Inflammatory Demyelinating Disease Surveillance Study
(UCID-SS)
BPSU facilitated Data Collection Follow-up Proforma**

Year 1 Year 2

Reporting Information
BPSU case ref: _____
Follow Up Date: _____
Date Today: _____
Case Definition (see protocol): _____

Details of clinician completing form:

Name: _____
Hospital name: _____
Telephone number: _____
E-mail: _____
Date completed: ___/___/___

SECTION 1 – PATIENT INFORMATION for anonymised linkage

Date of birth (dd/mm/yyyy): ___ / ___ / ___

Sex: Male Female

NHS number: _____

Is the child is still under your care? Yes No Discharged

If No to whom has the child been referred to:

Consultant name: _____ Hospital name: _____

SECTION 2 – FURTHER EPISODES OF DEMYELINATION

2.1 Any further episodes of demyelination over the past 12 months? Yes No How many? _____
 (If No- go to section 3)

2.2 Nature of episodes: please complete one page for each subsequent episode.

DATE of episode (dd-mm-yyyy): ____/____/____	
<p>SIGNS AND SYMPTOMS:</p> <input type="checkbox"/> Bilateral visual loss (involvement of both eyes within 30 days of each other) <input type="checkbox"/> Unilateral visual loss (one eye only) <input type="checkbox"/> Double vision <input type="checkbox"/> Intranuclear Ophthalmoplegia <input type="checkbox"/> Facial pain and numbness <input type="checkbox"/> Loss of sensation (one side of face only without facial pain) <input type="checkbox"/> Other Cranial Nerve signs: _____ <input type="checkbox"/> Weakness (one side of face only) <input type="checkbox"/> Loss of sensation (one sided, involving face, arm and leg) <input type="checkbox"/> Weakness (arm and leg +/- face, all on same side of body) <input type="checkbox"/> Loss of sensation (both legs and/or both arms at the same time)	<input type="checkbox"/> Weakness (both legs and/or both arms) <input type="checkbox"/> Bladder retention +/- bowel dysfunction <input type="checkbox"/> Loss of balance (gait ataxia) <input type="checkbox"/> Impaired co-ordination of arms/legs (limb ataxia) <input type="checkbox"/> Confusion or impaired alertness (encephalopathy) <input type="checkbox"/> Fever <input type="checkbox"/> Neck Stiffness <input type="checkbox"/> Headache <input type="checkbox"/> Seizures <input type="checkbox"/> Dizziness +/- nausea <input type="checkbox"/> Fatigue <input type="checkbox"/> L’Hermitte’s symptom (electrical sensation down the back produced by bending the neck forward). <input type="checkbox"/> Other (please specify): _____ _____
Brain MRI	Date (dd-mm-yyyy): _____ White matter lesions (Y/N): _____ <input type="checkbox"/> Not done/ Information not available
Spinal MRI	Date (dd-mm-yyyy): _____ White matter lesions (Y/N): _____ <input type="checkbox"/> Not done/ Information not available
CSF Oligoclonal Bands	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not done <input type="checkbox"/> Unknown or Not asked
Acute treatment used	Medications: Duration: Side effects:
Diagnosis given	<input type="checkbox"/> MS <input type="checkbox"/> ADEM <input type="checkbox"/> CIS <input type="checkbox"/> Transverse myelitis <input type="checkbox"/> Optic neuritis <input type="checkbox"/> NMO <input type="checkbox"/> Other; specify:
Did the child die?	No <input type="checkbox"/> Yes <input type="checkbox"/> Date: ____/____/____ Cause of death: _____

Please photocopy page and complete if further episodes have occurred

SECTION 3.CURRENT FUNCTIONAL STATUS

- When was the Date of last clinic visit? ____/____/____

MOBILITY/ MOTOR:

a. Does the patient have a motor impairment or limitations on mobility?
 No Yes (If yes tick one box in each section) Unknown

<input type="checkbox"/> Limits participation because of gait, no aids required <input type="checkbox"/> Uses aid occasionally <input type="checkbox"/> Uses aid for majority of time <input type="checkbox"/> Wheelchair –also walks for short distances <input type="checkbox"/> Wheelchair-dependent	the primary cause of limited mobility is: <input type="checkbox"/> Ataxia <input type="checkbox"/> Hemiparesis <input type="checkbox"/> Quadriplegia <input type="checkbox"/> Diplegia
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b. Were there any difficulties with fine motor skills? _____

c. Did the child have upper limb ataxia? _____

d. Does the child receive therapy (such as physiotherapy, occupational, speech therapy?)
Unknown No Yes (please specify) _____

VISION:

Visual acuity: right eye ___/___ left eye ___/___ (best corrected acuity) Unknown

<input type="checkbox"/> Normal vision (visual acuity 6/9 or better) <input type="checkbox"/> Decreased vision, but not registered visually impaired (6/12 or better) <input type="checkbox"/> Registered with partial visual impairment (6/60 or better) <input type="checkbox"/> Registered severely visually impaired (worse than 6/60)

COGNITIVE:

<input type="checkbox"/> No concerns <input type="checkbox"/> Above average/ Normal (functions well in school) <input type="checkbox"/> Minimal difficulties (on special education needs register, or School action support) <input type="checkbox"/> Moderate difficulties (statement of education) <input type="checkbox"/> Severe difficulties (Special School) <input type="checkbox"/> Unknown or not asked

BOWEL/BLADDER:

<input type="checkbox"/> Normal age-related bedwetting/soiling <input type="checkbox"/> Minimal (urinary hesitancy/urgency but no bed wetting/soiling) <input type="checkbox"/> Moderate (loses bladder/bowel control rarely <1x/wk) <input type="checkbox"/> Severe (loses bladder/bowel control >1x/wk) <input type="checkbox"/> Unknown or Not asked

Other SELECTED SYMPTOMS and SIGNS

(Please add comments below):

Has the patient suffered from Fatigue affecting activities of daily living?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not asked	
Has the patient suffered from focal symptomatic Seizures?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not asked	
Has the patient suffered from symptoms of depression requiring further psychological input?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not asked	

Thank you for your time and help in completing this questionnaire.

Please return all 3 pages in the prepaid envelope to Dr Michael Absoud, Fourth Floor, Institute of Child Health, Birmingham Children’s Hospital, Birmingham B4 6NH