

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

BPSU case ref. _____

REPORTING Instructions: Please report children (younger than 16 years) experiencing clinical neurological events consistent with site specific inflammatory CNS demyelination and confirmed with **white matter changes on MRI** (except in optic neuritis) as in table on page 2. Please only report children presenting with their **first** demyelinating episode.

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: _____

Has the patient been referred to you from another hospital? Yes No

If Yes, please give: Name of referring Consultant: _____ Hospital: _____

Home Post Code (First half only):

Ethnic Origin:

White

Mixed; please
specify _____

Asian or Asian British:

Indian

Black or Black British:

Pakistani

Caribbean

Bangladeshi

African

Chinese

Any other Black Background

Other Ethnic group; please
specify _____

Was the patient born in the UK? Yes No if no: specify country of birth: _____

REPORTING INSTRUCTIONS (please tick):

Condition	Reporting Definition
Acute Disseminated encephalomyelitis (ADEM) <input type="checkbox"/>	Any case with: (i) Clinical event (subacute/acute, poly-symptomatic and includes encephalopathy) due to a presumed inflammatory or demyelinating cause affecting multifocal areas of the CNS. (ii) MRI white matter changes.
Clinically Isolated Episode (CIS) <input type="checkbox"/>	Any case with a first acute clinical episode of CNS inflammatory demyelination (monofocal or multifocal but does not include encephalopathy) with white matter changes on the <u>MRI</u> .
Transverse Myelitis <input type="checkbox"/>	Any case with weakness and/or numbness of both legs (with or without involvement of arms) and supported by demyelination on <u>MRI</u> spine.
<input type="checkbox"/> Optic Neuritis	Any case of subacute/acute loss of vision with a presumed demyelinating origin.
<input type="checkbox"/> Neuro-myelitis optica (NMO)	Please report any case of optic neuritis and associated myelitis.

SECTION 2 – CLINICAL FEATURES

2.1 Onset of demyelinating event (dd/mm/yyyy): ____ / ____ / ____

2.2 Date of admission: ____ / ____ / ____

2.3 Did the child die before discharge? No Yes: Date of death: ____ / ____ / ____

Cause of death on death certificate or from post-mortem results: _____

2.4 Demyelinating signs and symptoms (Mark all that apply)

<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): _____ _____
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2.5 Was an MRI performed?: Yes but CT was performed first Yes No Unknown

If Yes: Brain with contrast Brain without contrast Brain – unknown if contrast used Spine

2.6 If performed, was the MRI abnormal?: Yes No Unknown

Please give date and details: _____

2.7 CSF:- positive for oligoclonal bands: Yes No Unknown Not done

2.8 CSF details:- WCC _____ x10⁶/L RBC _____ x10⁶/L protein _____ g/L

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

2.9 Other relevant investigations:

VEPs/ERG Unknown No Yes _____
 EEG Unknown No Yes _____
 NMO Antibody Unknown No Yes _____
 Other Unknown No Yes _____
 Microbiology infectious agent identified _____

2.10 Did the child require treatment? Yes No

Treatment	Tick if applies	Details (drug name, dosage, number of days)
IV Methylprednisolone		
Oral prednisolone		
Intravenous Immunoglobulin		
Antimicrobials used (eg antibiotics/antivirals)		
Anti-epileptics used		
Intensive care stay		

2.11 Was the possibility of future recurrent demyelination (i.e. multiple sclerosis) discussed with the family?

Yes No Unknown

SECTION 3 – RELEVANT MEDICAL AND FAMILY HISTORY
3.1 Is there a known patient history of (*important for consideration of the differential diagnosis*):

- Autoimmune Disorder (eg. diabetes, thyroid disease, JIA, SLE):

Yes _____ No Unknown

- Other medical history:

Yes _____ No Unknown

- Does the patient have prior developmental delay, known neurological condition, visual impairment or learning difficulties: Yes No Unknown

If Yes, please specify; _____

3.2 Is there a family history of:

Multiple sclerosis: Yes No Unknown; Relationship to patient: _____

Autoimmune Disorder: Yes _____ No Unknown; Relationship to patient _____

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

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