



BRITISH PAEDIATRIC NEUROLOGY SURVEILLANCE UNIT

Application Form

Please use the space provided to complete this form. Please read questions carefully as failure to provide sufficient detail may lead to a delay in processing the application or its rejection.

1) Title of study:

2) Investigators (Indicate Principal Investigator)

Please list all investigators involved in the study, their job title, affiliation, and contribution to this study. Please also indicate clearly the principal contact for correspondence on this application, giving a full contact address, email address and telephone number. (If more than four, please insert an additional row).

	Principal investigator: name and contact details	Job title and affiliation
1		
	Additional investigators: names	
2		
3		
4		

3) Proposed starting date:

Proposed duration of study:

Proposed territorial coverage:

Please tick one response.

UK and Ireland **UK only** **Regional**

4) Case definition

Please give careful thought to providing a precise and practical definition (based on symptoms/signs/investigations) that will be understood by paediatric neurologists. Use an internationally accepted case definition if at all possible and reference previous studies if relevant.

Case definition:

Age range for cases:

Inclusion criteria:

Exclusion criteria:

5) Expected Numbers

Please supply an estimate of the number of cases expected each year, i.e. yearly incidence rate. Provide a reference or an explanation for this estimate. Please also indicate the source of denominator data for calculating incidence.

Expected numbers (per year):

Source of denominator data:

6) Ethical approval

The majority of studies will require research ethics committee (REC) approval.

- If this is an audit study that does not require formal ethical approval, please forward to the BPNSU a copy of the confirmation from your REC that ethical approval is not needed.
- If this study does have ethical approval, then please forward a copy of the ethics application and a copy of the approval letter.

7) Research questions/surveillance objectives

Please indicate below the type of study that you are intending to undertake. **It should be noted that the BPNSU is only acting as a conduit between the investigator and anonymised cases. It does not provide any direct contact with patients.**

- Surveillance
- Case Registry
- Incidence or Prevalence study
- Cohort study
- Case-control Study
- Interventional Study (e.g. therapeutic trial)
- Audit

8) Methods

Please provide clear details of the study methodology you intend to employ to answer your research questions. Please forward a copy of your study protocol and/or COREC form with this application form.

9) Alternative sources of data

Will alternative sources of data, other than the BPNSU, be used for case ascertainment (e.g. laboratory data, hospital activity analyses etc)?

Yes

No

If yes, please describe:

- a) the sources you intend to use (add any statements of support as appropriate)
- b) the purpose of this additional source
- c) how data will be collected and then matched between sources
- d) the proposed analysis you intend to conduct

- Has your questionnaire been piloted?

Yes

No

- Is a follow-up questionnaire planned?

Yes

No

If yes, please give details (including timing of follow-up).

11) Funding arrangements

Please outline the funding arrangements for your study. BPNSU costs are £200 per year per study. Funding arrangements should not only cover the BPNSU fee costs but also administrative costs including research assistance/secretarial salaries/stationery/postage etc.

The BPNA will send an invoice to you when your study is accepted onto the BPNSU website. Please provide the following information:

Purchase order number:	
For the attention of:	
Full postal address:	
	Postcode:

12) Organisational arrangements

Please state the person responsible for the following:

- Person responsible for day-to-day administration (receiving reports, sending out questionnaires, correspondence with the BPSU):.....
- Person responsible for scientific management of the study:.....
- Person responsible for responding to clinical questions:.....
- Person responsible for collating and analysing results:.....
- Additional academic or statistical support available:.....

Please ensure that copies of all draft questionnaires and a signed letter of understanding are attached.

Signed: _____ Date:
(Principal investigator)

Name (in capitals): _____

Attached documents checklist:

BPNSU Letter of Understanding	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Questionnaire:	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Ethical Approval/Exemption:	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Copy of COREC application	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Study Protocol:	Yes <input type="checkbox"/>	No <input type="checkbox"/>