

Guidelines for Centres: Provision of pseudonymised data for BRAIN UK studies

Requests including clinical data

Some BRAIN UK applications include a request for basic clinical data.

Please note that researchers only have approval for the data items included in their BRAIN UK approved application.

Given the amount of work that could be involved, you might agree that:

- The retrieval of data be performed on a collaborative basis.
- The costs associated with retrieving the data are covered by the researcher.

BRAIN UK Ethical Approval

BRAIN UK ethics allows the provision of clinical data/pathology reports etc. providing that the data is provided to the researcher in a pseudonymised format.

Data Items that can be included

The following items can be supplied to the researcher:

- Lab Number (this is the link used by Centres/BRAIN UK)
- Text of Report
- Diagnosis/Conclusion
- Gender
- Age at death/at operation
- Other clinical data such as treatment/imaging/survival data

Data Items that should not be provided

Please ensure that any clinical reports and/or digital slides have been redacted so that none of the following information is included.

The following items cannot be supplied to the researcher:

- Name
- Date of birth (*age at death/age at operation are acceptable*)
- Patient Address
- NHS/Hospital Number (*only identifier provided should be lab number*)
- Ward information
- Name of medical staff, e.g., name of neuropathologist/clinical consultant
- Date of death/date of operation (*year acceptable*)
- Date sample received by the lab/date of report
- No actual dates should be supplied.

If the request is looking at timescales, e.g., date of diagnosis to date of treatment etc., this information should be provided as time intervals from one event to the next:

Event	Time Interval (days)
Diagnosis	Day 1
Radiotherapy started	Day 43
Death	Day 291