

## Summary

The UK Brain Bank Network (UKBBN) database holds data on brain and spinal cord tissue samples that are available from each of the 10 brain banks across the UK. Data are stored for each brain on the date of death, the age of the donor at death to the nearest year only, gender and ethnicity of the donor but no other personal identifiers, together with information on clinical findings, medication history, cause of death, neuropathological findings, scope of consent for research (i.e. whether including commercial research, genetic research, and research involving the use of the tissue in animal studies) and the availability of different types of tissue (frozen, fixed, paraffin-embedded, cerebrospinal fluid). In some cases, information is also held on gene polymorphisms or mutations that are associated with increased or decreased risk of neurological disease. The information is all provided by the individual brain banks in the MRC UK Brain Bank Network, all of which have their own research ethics approval for the collection and storage of brain tissue samples and accompanying patient data, and for function as research tissue biobanks.

## Obtaining access to the database

Access to the database through the web interface is password-protected. Potential users must first be approved and registered to use the system before they can log in and access data.

Applications for registration are made through the following web interface:

<https://brainbanknetwork.cse.bris.ac.uk/Account/UserRegistration>. Each request for access has to be supported by a short justification, with an academic institution/NHS email address provided for the applicant and his/her senior supervisor. Applications from outside these areas, e.g. from industry, have to include a more detailed justification as to why access is requested. The application will be considered by the Local Assessment Team. An applicant may be contacted for additional information. Once the request is approved, the applicant is sent by email a unique login to allow access to the searchable online database. Requests may be forwarded to the South West Dementia Brain Bank Governance Committee for advice, and, if needed, to the MRC Brain Banks Steering Committee if a decision cannot be made locally or if an applicant appeals against a rejected application.

## Refusal of access

Reasons for refusing access include but are not limited to the following:

- The applicant is not a bona fide researcher.
- There is a lack of availability of data/samples relevant to the application.
- The proposed work, in the view of the Local Assessment Team and South West Dementia Brain Bank Governance Committee, risks bringing the UK Brain Bank Network into disrepute.
- The proposed work risks the disclosure of identifiable information relating to any individual donor.
- The proposed work is outside the scope of the ethical approval, or the funders' terms, or University of Bristol's policies and procedures for use of the database.

## Access to tissue samples

The Local Assessment Team and South West Dementia Brain Bank Governance Committee are responsible for approving or rejecting requests for access to the database *but not for approving or rejecting requests for tissue samples*. The latter requests will be assessed by the management committees of the individual brain banks, in accordance with their individual operating procedures and research governance policies.

## Responsibilities of users of the UKBBN database

This section summarises the main responsibilities of any person wishing to use the UKBBN database. The same rules apply to all users regardless of whether they are a member of brain bank staff, a new user or a long-term user.

- Users must not share their passwords for obtaining access to the database and must report any use of the database by unauthorised persons to the Senior Database Manager ([richard.cain@bristol.ac.uk](mailto:richard.cain@bristol.ac.uk)).

## UKBBN Database Access Policy v1.0, released October 2017

- Approval for access to the database must be limited to the purposes described in the application form at the time of registration of the user. Any intended change in purpose must be notified by email to the Senior Database Manager and approved in advance.
- Users must not share information obtained from the database, except for the purposes described in the application form.
- The use of the database should be acknowledged in any publications or other research output that is based on the analysis of data stored within the database.
- If a publication or other research output is based in any part on the use of the additional information in datasets uploaded by researchers following the analysis of tissue samples provided by the UKBBN, those researchers must be acknowledged, and the unique URL of their uploaded dataset should be cited in the resulting publication or other research output.