Collection of Nervous System Tissue and/or Blood for Future Research Use

BRASH - Brain Tissue Bank South West

Exceptional healthcare, personally delivered
We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

Thank you for reading this.

What is the purpose of this project?

We wish to collect and store (“bank”) blood and tissue samples from patients with brain and spinal disorders to support future research into the cause, diagnosis, treatment and outcome of such disorders. Some of these studies may include genetic research aimed at understanding the way in which genes (molecules instructing cell division and growth) influence the behaviour of these disorders. Researchers in Bristol and elsewhere will be able to access the tissue and blood collection subject to ethical approval.

Why have I been chosen?

You are being asked to take part in this project because you are being investigated for a disorder of the nervous system (brain, spinal cord, nerves, or pituitary gland). Your management includes surgery during which tissue is removed routinely for access, diagnosis or treatment. We would like to ask you whether you would be willing to allow this tissue and any blood samples to be included in the research collection (tissue bank).
Do I have to take part?

NO, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Your management and treatment will not be influenced in any way whether you wish to take part or not.

What will happen to me if I take part?

- Participating in this study by donating samples to the tissue bank will not affect your treatment in any way. The length of your operation and stay in hospital will not be affected and no additional surgery will be performed.

- We will ask you to give us permission (signed consent) to include samples removed as part of your surgery in our studies. It will not involve taking any tissue additional to that routinely removed for access, diagnostic or treatment purposes.

- Tissue will only be stored for research use once all diagnostic needs have been met.

- You will be asked to give a blood sample at various times during your treatment in order to check how your treatment is affecting you. If you give permission for a blood sample to be stored for research extra blood will be taken on some of these occasions, but no additional venepuncture will be required.

- We will ask you for permission to consult your medical records at North Bristol Trust (or other relevant medical records elsewhere) for some information relevant to your illness.

- This information will include your age, gender, type and site of surgery, pathology diagnosis, epilepsy history, radiological (X-ray) features, your medical treatment and the response to treatment.
To take part in this study, we will have all that we need for our research and will not need to contact you. Blood and archival tissue samples will be treated as gifts to research and held under the care of the Tissue Bank within the usual diagnostic archive, in accordance with Human Tissue Authority regulation.

**What are the possible disadvantages and risks of taking part?**

There are no disadvantages or risks to taking part.

**What are the possible benefits of taking part?**

There are no specific benefits to you directly, but the results of investigations using this tissue may help others with similar disorders.

**What happens to tissue in the bank?**

Tissue will be securely stored until allocated to an ethically approved project. During analysis some will be “used up”. This allocation will go on until the supply is exhausted.

**Will my taking part in this study be kept confidential?**

YES. If you agree to take part in this study, only the relevant information mentioned above will be extracted from your records. Any information about you released by the Tissue Bank will have personal details such as your name and address removed from it. The same will apply to the tissue samples used in any laboratory studies. The information and tissues will only be known by a research number, which will prevent researchers from knowing your identity.
What will happen if I don’t want to carry on with the study?

Any unused tissue or blood stored in the Tissue Bank will be transferred to the diagnostic archive and stored or disposed according to departmental diagnostic protocols. No further allocations will be made to research projects. Data from previously allocated tissue or blood may already exist and will remain associated with those projects anonymised to the researcher.

Will any genetic tests be done?

DNA derived from tissue may be examined for abnormalities, which may give information on the cause of a disorder. It is unlikely to produce results with a direct influence on you or your relatives.

What happens if something goes wrong?

The planned research will have no influence on your treatment. The banking of your tissue or blood for research carries no risk. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated, the normal National Health Service complaints mechanisms will be available to you.

What will happen to the results of the research study?

Results will be presented at conferences and published as scientific papers, but you will not be identified in any report or publication. Results obtained from your specimens are unlikely to include information of immediate clinical relevance, but should anything helpful be found, this will be conveyed to your treatment team.
Who is organising and funding the research?

The neuroscience tissue bank is organised by neuropathologists, neurosurgeons, oncologists and researchers at North Bristol Trust. Funding for tissue banking is obtained from Neuroscience Charitable Funds and from ongoing project funding. None of the members of the brain tumour tissue banking team are being paid for their participation in the project. Future research studies utilising banked tissues will be funded by a variety of funds/charities.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you very much for reading this information sheet.
NHS Constitution. Information on your rights and responsibilities. Available at www.nhs.uk/aboutnhs/constitution
If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

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