

# Information Sheet-Neurosurgical

Version 1.1

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When someone undergoes neurosurgery, some brain tissue is often removed. This will usually be sent for testing in a pathology lab. Sometimes there will be a small amount of normal tissue that does not need to be tested. We would like to ask you if we can be allowed to keep this tissue for research into the functioning of the brain.

No extra samples will be taken, and the tissue we are interested in would normally be disposed of as surgical waste.

You do not have to agree to this and refusal would not affect your medical care in any way.

We realize that not everyone will wish to consider the idea of donating tissue. If you feel it is not for you then we will fully understand if you do not wish to read further.

## Newcastle Brain Tissue Resource

Information about  
donation of surplus  
neurosurgical tissue  
for research into brain  
disorders

## What's involved?

You have a neurosurgical procedure planned. Your surgeon will have explained to you exactly what this will involve. We will not interfere with this in any way. We would just like your permission to collect and retain any samples of brain tissue that are removed during the course of your operation that are not needed for diagnosis. These would usually be very small, but would still be extremely valuable in research terms.

## What is the Newcastle Brain Tissue Resource?

The Newcastle Brain Tissue Resource (NBTR) is a licensed tissue bank based at Newcastle University. It operates to standards set by the Human Tissue Authority and complies with all current legislation and guidance for working with human tissue. Tissue samples are provided to applicants whose projects are approved by the NBTR committee (this has both scientific and lay members and an independent chair who is not involved in the research). Over the last 40 years, research using tissue from the NBTR has made significant contributions to understanding both normal brain ageing and brain disorders such as: Alzheimer's disease, Lewy Body Disease, vascular dementia, Parkinson's disease, motor neurone disease and depression.

Most of our work is focussed on age-related disorders and the changes in the brain associated with these. As people are living longer, these disorders are becoming an increasing problem and there is still no substitute for examining samples of real brain tissue including tissue from those without these diseases. We also look at disorders of the brain that can occur in younger people including depression, anxiety and autism. The brain is very complex organ and it is not usually possible to take samples in the way that we can from other parts of the body (blood for instance). Currently most of the tissue we study is from those who have generously agreed to donate after their deaths and we are very grateful for this very valuable resource for researchers. However, there are some things which can only be established from those who are living.

## How can you help?

Examination of neurosurgical samples would enable researchers to increase their understanding of the changes that occur throughout a person's lifespan, and to check that any effects they may see in post mortem tissue are also valid in the living. We need to examine samples from those who do not have age related diseases as well as those who do.

## What would happen?

If you agree to allow us access to these samples it would have no effect at all on your operation. No extra tissue will be taken. Some tissue samples would be sent to the pathology laboratory in exactly the same way as usual and the pathologist would carry out whatever tests were required. Some of the tissue that is removed at this time would normally be disposed of. The only difference would be that instead of disposing of any surplus tissue in the usual way, it would be kept for research. We would collect the tissue and transport it securely to our tissue bank where the tissue will be preserved for future use, or in some cases used immediately in research.

## What kinds of research would it be used for?

Newcastle Brain Tissue Resource (NBTR) supplies samples to researchers for projects that they can demonstrate are scientifically and ethically sound. There is a rigorous approval process to make sure that samples are only used for high quality research. NBTR generally supplies samples for research into dementia and neurodegenerative disease, but also provides samples for many other disorders that affect the nervous system. This might involve looking at nerve cells and blood vessels under a microscope, finding out if certain chemicals change in tissue, or growing the cells in the brain in a culture dish to see how they work. Many samples are supplied to academic institutions both within the UK and worldwide. Where samples are sent outside the UK, we ask for confirmation that the work will be carried out to the same high research and ethical standards. Sometimes samples are requested by commercial companies - often working in partnership with NHS and academic institutions. This is in line with our policy of encouraging research that may lead to future treatments. Neither scientists nor relatives receive any extra financial benefit from this commercial work. It is rare that tissue will be used directly in projects with animals but many projects such as development of new drug treatments may have involved work with animals in the early stages. Some studies involve genetic (DNA) analysis of samples but this does not usually generate information that is useful to individuals.

You are at liberty to refuse permission for samples to be used for any of these purposes if you wish.

Brain banks are run as 'not for profit' organisations but because of the high running costs involved, those requesting tissue are asked to make a contribution if possible, using standard costs as recommended by the Medical Research Council.

## What about confidentiality?

Your samples are provided anonymously. Samples would be stored labelled only with a number. Samples issued to researchers would be labelled only with this number and they would never have access to any information that might identify you.

We would not enter any identifiable information about you on our database, although we would record your age and gender and the type of neurosurgery to help us understand any changes we may see. We would need to keep a copy of your consent form but this would be filed securely in a locked filing cabinet in a locked office. We will not know anything about you without your agreement.

## What are the possible risks and benefits of taking part?

There will be no extra risks attached to donating these samples for research but equally there will be no benefit for you personally. Your tissue samples will though, potentially contribute to studies that will benefit others in the future.

## Can I withdraw from the research?

You can change your mind about donating samples at any time prior to the operation. Once they have been donated samples can still be withdrawn by contacting the NBTR manager at any time prior to their being issued to researchers. After this withdrawal is not possible although any samples remaining in the tissue bank will be disposed of on request.

## Further Information

If you need any more information about donating your tissue samples, please contact us at:

Newcastle Brain Tissue Resource

Edwardson Building  
Newcastle University  
NE4 5PL

0191 208 1231  
nbtr@ncl.ac.uk

## How will we use information about you?

We will need to use information from you, and from your medical and study records for this research project.

This information will include your NHS number, name, contact details and details of your medical history. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

## What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

## Where can you find out more about how your information is used?

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- by asking one of the research team
- by sending an email to [nbtr@ncl.ac.uk](mailto:nbtr@ncl.ac.uk)
- by ringing us on 0191 2081231

## What can I do if I have a complaint?

- Complaints or concerns can be raised with the NBTR manager on 0191 2081231 or [nbtr@ncl.ac.uk](mailto:nbtr@ncl.ac.uk) or with any member of the research team
- If you prefer you can talk to the Patient Liaison Service 0800 032 0202 or [NorthofTynePALS@northumbria-healthcare.nhs.uk](mailto:NorthofTynePALS@northumbria-healthcare.nhs.uk)
- If your concerns are about donated tissue the Newcastle University Quality Assurance team can be contacted via [humantissueresearch@ncl.ac.uk](mailto:humantissueresearch@ncl.ac.uk)