

Position paper: Biobanking

This document provides an overview of biobanking, The Brain Tumour Charity's position, and what we are doing to address the issues raised.

What is biobanking?

Biobanking is the process of collecting and storing biological samples for the purpose of research. Biobanks typically store health information about an individual such as sex, age, diagnosis and history of disease, as well as biological samples such as blood and tissue.

When a child or adult undergoes surgery for a brain tumour a sample of their tumour (known as tissue) is taken for a biopsy to diagnose their tumour. There are over 130 types of brain tumour and a biopsy can help determine tumour type and characteristics, such as genes that may be more or less prevalent than in a healthy brain. Genetic traits are now even more significant. In 2016 The World Health Organisation released a revised edition of the "2007 Classification of Tumours of the Central Nervous System" which details how each type of brain tumour is identified (1). It expanded the types of information that will lead to a more accurate diagnosis, and now includes a number of genetic changes and more details about what the tumour looks like down a microscope.

Once the medical team have made the diagnosis any additional biological samples may be removed and stored in a biobank for the purpose of research. In some instances multiple samples can be taken at the point of diagnosis as well as after any additional surgeries. This allows researchers and clinicians to track changes in the disease in response to treatment over an extended period of time.

Researchers and companies that look at why and how tumours grow or develop new treatments may request tissue from a biobank. Analysis of tumour tissue can advance knowledge of the disease and may contribute to improvements in diagnosis, treatment and care for everyone affected by a brain tumour in the future.

There are rules, regulations and codes of practice around consent and confidentiality for the collection, storage and release of biological samples and health information (2–5). Biobanks are licensed by the Human Tissue Authority to store biological samples for use in research and researchers must have Research Ethics Committee Approval (2). It is standard practice for biobanks to release anonymised information in order to protect the identity of the donor.

A biological sample may be taken for a biopsy and then stored for the purpose of research. It is preferable to seek consent from the potential donor (5). This is usually done by a healthcare professional and it should be made clear what the general purpose is. Parents can give consent on their child's behalf (6). Consent can be generic which means that the donor agrees in principle to the use of samples in research and the use is not time limited (5). Alternatively, consent can be for a specific research project or limited period of time. A donor can withdraw consent at any time.

A patient may consent to a biopsy but not be made aware of the potential of their sample for research. If the sample is stored in a biobank researchers could access the sample only if they have Research Ethics Committee Approval for a specific research project and samples have to be made anonymous to researchers in order to protect the identity of the donor (3,6).

Researchers can learn from about a disease from a brain post-mortem. An individual can consent to brain donation in their Will, however the brain should be taken immediately post-mortem at which point the Will may not have been read (7).

The Brain Tumour Charity's View

We believe that every patient has the potential, and the right, to be a research patient. Brain tumours are rare and so it is important that we learn from each and every one. Biobanks are an invaluable resource to help us better understand brain tumours and it is essential that biological samples are routinely collected, and that researchers have access.

A donor's biological samples and linked information can contribute to advances in research which may benefit others who are affected by the disease. With a large collection of samples researchers can analyse genetic differences and more accurately group tumours by sub-type. We have co-funded research to analyse the genetic makeup of the aggressive Group Three subtype of medulloblastoma – a type of brain tumour common in children. Biological samples sourced from biobanks allowed the research team to identify genetic properties and distinguish Group Three from other subtypes of medulloblastoma. Early results showed that activation of one particular gene is linked with more aggressive development of this type of tumour. This discovery enables clinicians to test if the gene is active in patients with a Group 3 subtype and investigate more targeted, stronger treatments. In patients where the gene is not active a less aggressive form of treatment may be appropriate which will reduce the risk of adverse side effects.

Despite the clear benefits of biobanks the collection of tissue for banking varies widely across the UK. There is often no infrastructure in place to collect tissue routinely, or in larger quantities. At present it is unclear how this need can be met. Currently, a limited number of adult tissue samples are stored in local banks across the UK with no single point of access, no uniform protocol and no centralised co-ordination. This may affect the quality and quantity of samples available. It also adds delay to research projects and additional administrative work which is an unwanted burden to researchers when charity and government funding is already stretched.

Longitudinal studies rely on multiple samples from the same patient at different times to look at changes over time and better understand how a tumour changes from diagnosis. Time and resource needs to be allocated to ensure collection and storage to allow these studies to take place.

There also needs to be a cultural change in our approach to biobanking. We know from experience that many people affected by a brain tumour are not asked if they wish to donate biological samples. However, 76% of patients who responded to a survey said they would be willing to undergo an additional operation to collect biopsy samples from their tumour even if this surgery was not for treatment purposes and would not benefit them directly (8).

A healthcare professional should seek generic consent and make it immediately clear to a potential donor that their biological sample could be used to benefit research. This helps engender trust, is more efficient and creates informed patients (5). People affected by cancer should be given information to make them more aware of the benefits of and opportunities for tissue donation for research and this will empower people affected to ask their clinician for more details.

What is currently available?

In paediatric cancers there is central tissue banking and this is in part a response to the limited and disparate number of cases of cancer in children. The Children's Cancer and Leukaemia Group (CCLG) Tissue Bank is co-funded by Cancer Research UK and CCLG and is formed of 19 biobanks across the UK (9).

The collection of biological samples from adults with a brain tumour for the purpose of research varies and is not centralised. Biobanks that store brain tumour samples may also store tumour samples from other cancers or disease groups. The size and scope of biobanks vary. For example, Manchester Cancer Research Centre collects from four Trusts in the region (10). Not all centres of care will have the facilities to bank samples and not all centres will have the resources to facilitate longitudinal studies.

The Governments of England, Scotland and Wales contribute funding to UK Biobank which collects samples across a range of disease areas. The Medical Research Council (MRC) is a non-departmental government body and co-funds The Brain UK, a virtual bank which facilitates access to archives of 26 NHS Neuropathology Centres. The purpose of the bank is to put researchers in contact with banks however there is no guarantee of access to the samples each centre is storing. The MRC also leads the UK Brain Bank Network which aims to "establish a co-ordinated network of brain tissue resources" across all neurological disorders.

There are a number of brain banks that collect brains post-mortem for the purpose of research. Some brain banks will focus purely on neuro-degenerative diseases such as Dementia. The processes for collection vary and The Health Tissue Authority (HTA) encourages prospective donors to contact a brain bank directly and make the necessary arrangements (11).

What is The Brain Tumour Charity doing?

There is a clear need to improve the routine collection of biological tissue with matched data and fluid samples, and make it easier for researchers to access samples. We want to facilitate the storage of brain tumour tissue in biobanks and ensure that the samples are accessible and available for high quality research projects.

Longitudinal studies are increasingly important in the study of brain tumours. We will work with the community to encourage longitudinal banking of samples at diagnosis, recurrence and autopsy for adult and paediatric brain tumour samples.

We will develop awareness campaigns amongst healthcare professionals and people directly affected by brain tumours, to highlight the benefit of banking biological samples for research. These campaigns will include information and resources to raise awareness and help start these conversations about gifting tumour tissue for research.

We will also raise awareness of the benefits of brain donation. We provide direct advice and guidance to those who contact us saying that they wish to donate their or a loved ones brain after they have died.

These aims are outlined in A Cure Can't Wait: Our Research Strategy 2015-2020 (12). To be successful we need to talk to researchers, healthcare professionals and people directly affected. Without their

experience and support it is not clear what an appropriate or workable solution is and we will not be able to use our funds in the best way possible.

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