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difference*

Patient Information Sheet:

Donating samples to the Daisy Tumour Bank for use in cancer research

Cancer research would not be possible without the participation of patients who are undergoing treatment within the NHS.

Research is important so that we can improve cancer detection and find better treatments for patients with cancer. The analysis of tissue and blood samples from patients is essential to further our understanding of cancer biology.

As a patient in the Hull and East Yorkshire Hospitals NHS Trust your clinical care team have suggested you may be able to help with this cancer research.

The Daisy Tumour Bank is licensed by the Human Tissue Authority as legally required. All handling of tissue by the Daisy Tumour Bank is regulated by the Human Tissue Act 2004.



Patient Information Sheet: Donating samples to the Daisy Tumour Bank for use in cancer research

We would like to invite you to donate samples to the Daisy Tumour Bank (University of Hull) for the purpose of cancer research. We would like to make it clear that donation is entirely voluntary and your care will not be affected if you choose not to participate. Before you decide, we would like you to understand why the research is undertaken 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. We suggest this should take about 10 minutes. Please ask us if anything is not clear.

What is the Daisy Tumour Bank and what is its purpose?

The Daisy Tumour Bank is a biobank, a facility to enable collection, storage and use of human blood and tissue (for example skin, bowel, lung or breast) for cancer research. The University of Hull is the custodian of the tissue and blood samples stored in the Tumour Bank. The Tumour Bank is creating a collection of samples to share with researchers for ethically approved research projects. It is hoped that research will improve understanding and knowledge of cancer, to benefit patients in the future.

Why have I been chosen and what would I need to do?

Your hospital has agreed to help the Tumour Bank collect samples from patients.

If you are about to undergo a surgical operation or biopsy procedure involving the removal of tissue as part of your treatment we would like your consent to donate a small amount of this tissue to be stored and used for cancer research. In many cases this tissue is surplus to what is required for diagnostic purposes. If possible we would also like to collect blood samples to accompany your tissue sample.

If you have been diagnosed with a blood cancer we would like your consent to donate blood samples to be stored and used for cancer research.

In the future you may undergo further procedures at Hull and East Yorkshire Hospitals NHS Trust. If you wish, you can also give your consent to donate future samples to the Tumour Bank, collected during your routine care. This would allow us to collect further samples from you, without approaching you to ask for your consent again. If you prefer we can approach you each time you might be able to donate to ask for your consent. You can indicate your choice on the consent form.

If you have previously undergone a hospital procedure where relevant tissue was taken for clinical purposes we may also be able to access this, with your consent, because surplus tissue is legally stored in the NHS laboratories after routine testing has been completed.

If you choose to donate, samples will be obtained as part of your routine care. You will not need to make extra visits to the hospital. You will need to sign a consent form to say that you agree to donate your tissue and/or blood to the Tumour Bank and that we can access your clinical data.

What kinds of samples are you interested in collecting?

Human tissue and blood are valuable for research. We would like to create various collections of human tissue and blood to enable a wide variety of research to be undertaken. We would like to collect small pieces of tissue up to the size of a large pea (approximately 1 cubic centimetre) per sample, which are surplus to diagnostic requirements; these samples may consist of tumour or normal tissue adjacent to the tumour.

We are also interested in blood samples from any patients with cancer for the purposes of research. If possible, we will collect blood samples at the same time you have your blood taken as part of your routine care. The volume of blood collected to accompany a tissue sample may be up to a maximum of about 5 teaspoons (approximately 25ml). The volume of blood collected from blood cancer patients may be up to 8 teaspoons (approximately 40ml).

Are there any additional risks to my health if I do take part?

Each type of procedure or surgery carries different risks. Additional risks which are related to obtaining research samples are usually minimal because samples will be taken during a routine procedure, which you will be undergoing whether or not you decide to donate any samples. However in some cases an additional procedure is required, with your consent, in order that tissue for research purposes can be collected. These procedures and risks will be discussed with you by a member of the Tumour Bank team prior to your agreement to consent.

What sort of research will be undertaken using my samples?

Donations of samples are extremely valuable to researchers to allow investigation into the causes and development of cancer, to assess new treatment options and to identify the genetic basis of disease. The methods used may include examination under a microscope or breaking up the sample to identify and measure the proteins inside the sample. A detailed analysis of DNA (the 'genetic code') in the sample may be carried out, which contains very useful information. Samples will not be used for any other purposes other than ethically approved cancer research.

Some research may include the administration of samples into rodents (rats or mice). This is only done when it is essential to further our understanding of how cancer develops or responds to treatment. Experiments are performed in accordance with strict Government guidelines and involve the minimum of distress to rodents used. If you do not wish to allow your samples to be used in research using rodents then please indicate this on the consent form.

What will happen to my samples after I have donated?

Your samples will be stored in the Tumour Bank until they are required for an ethically approved research project. Samples are stored in secure -80°C freezers in a secure laboratory. The freezer temperatures are monitored to ensure your samples are preserved, as they are very precious. Samples will be stored anonymously so researchers will not be able to identify you. Only suitably trained Tumour Bank staff will have access to your samples.

Researchers within the UK and European Economic Area may apply to use samples from the Tumour Bank for their cancer research. Research projects will be assessed by the Tumour Bank Access Committee in accordance with the Access Policy, to ensure samples are only released for

projects which are of scientific value and ethically approved. Research may be undertaken by third parties including universities, the NHS, biomedical research institutions or commercial organisations.

What about my privacy?

You have a right to privacy and as such we take this seriously. Under the Data Protection Act (1998) we are responsible for maintaining the confidentiality of any information we hold about you. In order to use your samples effectively we will obtain relevant clinical data relating to your diagnosis, treatment and any ongoing follow up. This information will be obtained from your clinical team and records in the Hull and East Yorkshire Hospitals NHS Trust or cancer registers, by NHS staff or Tumour Bank staff who have an Honorary NHS contract (which binds them to the same confidentiality rules and regulations as NHS staff). Your samples and clinical data will be stored securely and confidentially. Researchers will have access to your samples and relevant clinical data but will not be able to identify you. Regulatory authorities may need to access the data we hold about you to ensure that we are working in accordance with applicable rules and regulations. Research data, which will be generated through the analysis of samples in the Tumour Bank is important and we may share this data with other research groups and data may be published publicly in a biomedical and/or scientific journal, however you will not be identified when any research data is shared or published.

What happens if you find out something which may affect my future health or that of my family?

It is very unlikely that we would receive information from researchers which may directly affect your treatment or your family. If this happens we will advise your consultant. If this is found to be of major impact you will be informed via the Hull and East Yorkshire Hospitals NHS Trust.

Will I receive any financial benefit?

No, your sample is donated as a gift. The Tumour Bank will not benefit financially from research on your sample. The Tumour Bank may recover costs from researchers accessing samples; these costs are associated with sample collection, processing and storage. If new tests or treatments are developed by commercial companies or academic research groups who then make a profit, it will not be possible for you or the Tumour Bank to make a claim. Such tests and treatments may benefit all of us in the future.

What happens if I change my mind?

Donation is completely voluntary and you are free to change your mind at any time, without giving any reason. Withdrawal will not adversely affect your medical care in any way. If you withdraw, any remaining samples which you donated will be disposed of in accordance with the Tumour Bank disposal policy. It will not be possible to destroy data already generated from research undertaken using your samples, but the Tumour Bank will not collect any further clinical data about you. If you wish to withdraw please contact the Tumour Bank (contact details are given below).

What would happen to my samples if the Daisy Tumour Bank closed?

In the unlikely event of closure of the Tumour Bank, we would endeavour to transfer any remaining samples in the Tumour Bank to another Biobank which is licensed by the Human Tissue Authority, for use in ethically approved cancer research. Your samples would be used in line with your wishes on the consent form. As a last resort, if it was not possible to transfer the samples to another Biobank then they would be disposed of in accordance with the Tumour Bank disposal policy.

Do I have to take part?

No, it is entirely voluntary. If you choose not to participate your care will not be affected. If you wish to participate we will ask you to sign a Consent Form to show you have agreed to take part.

Where can I find out more?

You can discuss issues raised in this information sheet with a member of the Tumour Bank team who would take consent from you. For further information please visit our website or contact the Tumour Bank directly (contact details are given below).

What happens next?

If you are interested in donating tissue or blood samples to the Tumour Bank please advise your NHS clinical care team. We will then arrange for a member of the Tumour Bank team to meet with you to discuss donation and answer any questions you may have.

Contact details and feedback on the consent process

Potential donors are welcome to give feedback on the consent process verbally, by telephone or in writing to:

Daisy Tumour Bank
HYMS, University of Hull
Daisy Building (2nd Floor)
Castle Hill Hospital
Castle Road
Cottingham. HU16 5JQ



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