

Frequently Asked Questions

General

● *What is onCore UK?*

onCore UK is a charity established to provide high quality cancer tissue samples, coupled to anonymous patient information, for research to discover new ways to prevent, diagnose and treat cancer.

Funded by Cancer Research UK, the Department of Health and the Medical Research Council, onCore UK has partnered with selected NHS trusts to form Biosample Donation Networks within the NHS. It has also linked up with other existing tissue banks to develop common standards for the collection and storage of samples, and IT systems to make it easier for researchers to find and access the samples they need.

● *A number of tissue banks already exist. Why do we need another one?*

The increasing number of potential new treatments for cancer, and the availability of new technologies for cancer research, has led to a growing need for human tissues to:

- Advance our understanding of the biology of cancer
- Identify new targets within tumours for anti-cancer drugs
- Evaluate how tumours respond to new and existing treatments

Many existing banks are too small for scientists to be able to carry out the kind of large scale studies that are needed. onCore UK will enable a national approach to the large-scale collection of high quality samples linked to anonymous information about donors, their disease and response to treatment.

● *Where is the bank located?*

onCore UK's offices are currently located in Borehamwood, Hertfordshire. However, donated samples are stored at a separate facility elsewhere. This facility was chosen after an extensive selection process because it offers state of the art facilities with a focus on safety and the delivery of high quality samples.

● *How will onCore UK keep abreast of changes in ethics/tissue law?*

Ethics, and the law, will be upheld in all circumstances by onCore UK. An independent Ethics and Standards Advisory Panel will provide advice to the management and trustees of onCore UK on the ethics of the use of human tissues in research and onCore UK has in house expertise and expert legal advisors to ensure legal compliance.

Collecting samples

● *How are the samples sourced?*

onCore UK is working with a number of NHS partners. Cancer patients at participating hospitals are asked if they would like to donate their tissues for research. Only tissues from patients who have given informed consent will be used and only if the tissues are surplus to those needed to care for the patient.

● ***Will donors be paid?***

No. Patients donate their tumour tissue and other biological samples for research to discover new ways to prevent, diagnose and treat cancer. All donations are made with informed patient consent and are essentially gifts.

● ***Are NHS Trusts paid for the samples they obtain for the bank?***

No. However, expenses incurred by NHS Trusts to provide the tissues will be passed on to onCore UK to ensure that precious NHS funds are not being used in that way. In turn, onCore UK may pass on these costs to researchers via a cost-recovery charging system.

● ***I have cancer and would like to donate to onCore UK. What does this involve and who do I contact?***

If you have been diagnosed with cancer you can choose to donate blood, tumour tissue and relevant clinical information about yourself to onCore UK for use by cancer researchers. You will need to read our information sheet 'Giving Tissue and Blood Samples for Cancer Research' (available at www.oncoreuk.org/pages/donors_routes.html or in print on request). If you are happy to proceed, a member of staff trained specifically for the onCore UK project will answer any questions you have and take you through the consent form (also available via the above link).

You would give a one-off blood sample, in a similar way to having a blood test. The hospital laboratory will provide us with any tumour tissues from biopsy tests or operations that are not required after your medical treatment, and onCore UK-trained staff will carefully collect specific clinical information relating to your cancer to accompany your samples. The samples and data are anonymised and made available for ethically approved cancer research.

This service is currently available in pilot regions, and we anticipate expanding to work with more regions over the next few years. Our active regions are Central South Coast, Pan-Birmingham and West Anglia. To find out how to contact your local Coordinator please see the 'Routes to donation' page on our website (http://www.oncoreuk.org/pages/donors_routes.html), email generalinfo@oncoreuk.org or telephone 020 8731 4588.

Consent and confidentiality

● ***Can samples be taken without patient consent?***

No. Patients and ethics are at the heart of onCore UK. Not only would it be against the law for samples to be taken without consent, but onCore UK has devoted much effort into developing an ethically approved patient consent form. No samples will be collected by or on behalf of onCore UK without first obtaining consent from a willing donor.

● ***How can patients be sure that their personal details are kept confidential?***

This information will only be used in research to find new ways of preventing, diagnosing or treating cancer. All records are anonymised, which means that information is only coupled to the patient's history and not to their personal identity details before they are provided to researchers.

● ***Can patients be consented to donate tissues to onCore UK and be consented for other studies?***

Yes, but this requires clinical judgement and the clear understanding of the patient. The patient should not be approached for consent to tissue donation if this could cause confusion about participation in more than one project. onCore UK will only accept a tissue donation if it does not compete with another clinical study.

● ***Can the onCore UK consent form be combined with the local Trust or other consent forms?***

Not without careful consideration and discussion. This is because the onCore UK patient information sheet and consent form have been approved by a Research Ethics Committee and there are restrictions on how it can be used. If you would like further information on this, please contact generalinfo@oncoreuk.org.

Access to samples

● ***When will the bank open for business?***

onCore UK, in collaboration with partners within the NHS, has begun collection of donated tissue samples. Researchers will be able to obtain samples from the bank in 2008.

● ***Can anyone get permission to access the patient information stored in the bank?***

No. The tissues and anonymous patient information stored in the bank are solely for use in research and researchers must go through a rigorous application process in order to access them.

● ***How much do you charge researchers to use the resource?***

onCore UK operates on a not-for-profit basis and does not buy or sell human tissue. Expenses incurred by NHS Trusts to provide the tissues will be passed on to researchers via a cost-recovery charging system. The fees levied from researchers will be based on the accepted ethical principle of recovering the fair costs of obtaining the samples and the running costs of onCore UK acting as custodians of the samples.

● ***Researchers pay for the tissue samples. Isn't this just profiteering at the expense of cancer patients?***

Not at all as onCore UK is a not-for-profit organisation and does not buy or sell human tissues. The fees researchers pay only cover the costs of running the service. Income generated will be reinvested in the organisation to allow more samples to be collected for the research community.

If you would like more information on any of the issues above or have additional questions, please contact generalinfo@oncoreuk.org.