

The ROYAL MARSDEN

NHS Foundation Trust

Using and storing samples in the Generic Tissue Bank for future research

Patient Information



NHS

Introduction

During your treatment and care at The Royal Marsden we may need to take samples as part of your routine individual care. You may have biopsies taken, undergo surgery to remove tissue, give blood for blood tests or provide other bodily fluids such as saliva, urine and faeces as part of your diagnosis and treatment.

We may keep and use these samples to help confirm a diagnosis and monitor your condition. The results of these tests will be given to you by your doctor and will be used to plan your care.

We are asking your permission (by signing a consent form) to store some of your leftover samples in a 'Biobank' (the Royal Marsden's Generic Tissue Bank) for future research. Consent is a freely given agreement, based on a full understanding of what is to happen. Your samples will be used by researchers to try and understand more about cancer and develop treatments with fewer side effects.

On this consent form we also ask your permission to take an additional 20ml (4–5 teaspoons) of blood, this is optional and it is entirely up to you whether you wish to agree or not. If you indicate yes, this sample will be taken along with your other blood tests, so there is no need for an additional visit.

What kind of research might be done on these samples?

Samples may be used in research to learn more about the causes of cancer and its treatment. This may include genetic research, for example, looking for changes in DNA (genes) that may cause cancer and culture of cells from the samples in the laboratory.

Researchers from leading scientific research institutes, both academic and from industry, in the UK and around the world can apply to use the samples we store for future research. All research projects must be approved by the Royal Marsden and Institute of Cancer Research's Committee for Clinical Research.

This committee reviews and monitors all research that is carried out at the Royal Marsden and ICR. This is to make sure that the research is in the interest of patients and is carried out safely and the project design is of sound scientific basis.

Samples may be used in animal research to identify new treatments for cancer. This type of research is strictly regulated and only conducted under government licence. You can opt out of giving your consent for this type of research on the consent form.

You may still be asked for your consent for other specific projects and clinical trials and those are not related to the samples in the GTB. For these projects, you will learn more about the research from your clinical team and specific consent would be requested from you.

Where will my samples be kept?

Any samples you donate to the Generic Tissue Bank will be stored in the laboratories at The Royal Marsden, who are licensed by the Human Tissue Authority (HTA) to collect and store such samples for future research.

In each laboratory where samples are stored access is restricted to authorised staff only and all storage areas are monitored 24 hours a day, 7 days a week. The Designated Individual at the Royal Marsden is named on the HTA Licence and has overall responsibility for the samples.

Who will have access to the samples and clinical data?

By signing the Tissue for Future Research consent form you are giving permission to the Biobank Team to have access to your medical records. This will enable them to collect the samples and issue them with a unique code which will anonymise them whilst in storage or in use. Once a research project has been approved by the Committee for Clinical Research, the researchers on the project will only receive the tissue and associated clinical data, which may include anonymised scan images, from the Generic Tissue Bank with this unique code.

You will not be identifiable to anyone beyond your clinical care team and the Biobank team.

What about confidentiality?

Samples kept in the Generic Tissue Bank do not have any patient details on them. They have a unique identifier (code) so that researchers receiving the samples and clinical data do not know your name or any other personal details (anonymised). Samples may only be traced back to the patient by authorised biobank staff or the patient's own clinical team, if required during regulatory inspections.

All staff at the Royal Marsden must work within the Trust's confidentiality policies and the data protection laws so all patient information is protected.

Anonymised samples from the Generic Tissue Bank and associated anonymised clinical data or anonymised digital images of your samples, may be transferred to researchers in external organisations or data resources (including commercial research organisations) outside the remit of General Data Protection Regulation (GDPR). This will always be done under written legal agreement which guarantees the use and safe keeping of the samples or data. No information about your identity (such as your name or date of birth) will be sent outside of the Trust. We follow standard practice where external researchers always agree in writing that they will not attempt to identify you as the patient, as there is always a theoretical possibility that your identity could be picked out from your data (for example from matching your genetic data or if you have a very rare condition).

Will you be able to tell me the results of any research on my samples?

The samples stored in the Generic Tissue Bank are for research that is currently unspecified and you will not benefit directly from the results of any research using your samples.

Whilst the results are unlikely to affect your care now, it may help people like you in the future by allowing researchers to learn more about what causes cancer and other diseases, and how to prevent and treat them. You will not personally gain financially or own any of the research data through the donation of your samples.

Any research results generated from using samples in the Generic Tissue Bank will be published on the Biomedical Research Centre website (www.cancerbrc.org) and may also be published in peer-reviewed scientific journals. No personal information will be available or published at any point.

Does this mean extra visits to the hospital?

No, you will not need to make any extra visits to the hospital. Any samples we may want to use for future research will be taken at the time of your routine visits.

If I agree, what do I have to do?

We will ask you to sign an e-consent form agreeing to the storage of samples in the Generic Tissue Bank and its use in future projects. This will stay on your medical records at the Royal Marsden so you will only need to complete it once. However, you can change your mind at any time, even after you have signed a consent form and any time in the future and after you have been discharged.

What if I do not wish to take part or change my mind?

Your agreement is completely voluntary. Whatever you decide, you will be given the best appropriate treatment and care.

You can change your mind at any time, even if you are no longer under the care of The Royal Marsden. You do not need to give any reason and this will not change your medical care. If possible we will ask you to sign a withdrawal of consent form and this will be stay on your medical records. Please speak to your clinical team or email biobank@rmh.nhs.uk if you wish to withdraw.

No further samples or data will be collected once consent is withdrawn. Those already stored, if they haven't been already used, will be destroyed.

Who do I contact if I have any questions?

If you have any questions, please call:

Biobank Team 020 8642 6011 ext 4705 or 4222

Email biobank@rmh.nhs.uk

The Royal Marsden Macmillan Hotline: 020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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royalmarsden.org

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