

Thames Valley Haemato-Molecular Diagnostic Service

Patient information sheet for the storage of tissue samples

Your doctor will have told you that the management of your illness requires that we perform blood and bone marrow tests. This routine practice is essential for diagnosis and for planning further treatment. However, in most cases more sample will be removed than is needed for these tests. The aim of this form is to ask whether we may keep the remainder of the sample(s) that has/have been removed, to use in our research. Storage will occur only if there is a surplus after your routine tests have been conducted.

We would like to use these samples in research to improve the diagnosis and the treatment of blood disorders. In your particular case examples of the type of research we might plan include: testing genetic material ie: DNA and RNA, growing cells from the sample in an incubator or animal experiments.

By signing this form, you will be giving us permission to store your sample for future research of this type. Any use that we may want to make of it in the future will have first to be approved by our local Research Ethics Committee, which is an independent panel of experts who assess all research projects for safety, ethical acceptability and who protect patients' interests. The work that we envisage will have no direct implications for your personal health. This may be because the sample cannot be identified as yours, or it may simply be because of the type of research involved.

However, in some circumstances we may wish to use sample material, which we can link back to you and your clinical record. Such research may have direct consequences for you or for your family. If it does, we would first ask the Research Ethics Committee and having obtained their approval for the research, we would always come back to you to explain the implications and would then ask your consent to proceed. You would, of course, have the opportunity to refuse permission at that stage.

If we do not believe our research will have implications for you or your relatives and the Research Ethics Committee approves the research without your further consent, then we will not ask your permission.

The information obtained from our research could be published anonymously in scientific journals and discussed at scientific and medical conferences. If we decided that it would be helpful to publish or discuss information about your case alone, it would still be anonymous but we would not go ahead without obtaining your consent again.

There is also the possibility that tissue, which cannot be linked back to you, may be used in the commercial development of medical technology. We would only ask for your consent to such development in relation to your tissue if for any reason it could be linked to you.

Many thanks for your consideration of this project. If you require any further information on this project please contact your medical team or myself

Dr Anna Schuh
Consultant Haematologist

Consent for storage of tissue samples for research

Thank you for reading this information about using and storing tissue and blood samples for research. Please read this form and sign below.

I have read and understood the patient information leaflet entitled 'donating tissue samples for medical research' and have had the opportunity to ask questions.

I agree to any excess tissue, and/or bone marrow and/or blood samples removed during the course of my diagnosis and/or treatment to be stored and used for research projects that have been granted ethical approval.

I understand that this research might involve looking at DNA and genetic changes that may cause blood disorders.

If I consent, I agree that the samples and clinical information about me will be stored at the Thames Valley Haemato Molecular Diagnostic Service (DNA/RNA) and the Oxford Biobank (cells and tissues).

All samples and clinical information will be anonymous.

There will be no financial benefit for me if this research leads to the development of any new tests or treatments.

I understand that my agreement is entirely voluntary and can be withdrawn at any time.

For further questions or concern about this I will contact my medical team.

Yes, I agree for any excess material to be stored for use in ethically approved research projects.

Patient Name (block letters)DOB.....

Signed.....Date.....

Please, give this form to your doctor once you have had the opportunity to ask questions.

Clinician taking consent

Clinician Name (block letters).....

Signed.....Date.....