

Donating Biological Samples for Research Information for Healthy Donors

We would like to invite you to help us to continue our research into the treatment of disease. It is up to you whether or not to take part. If you would like to help, this leaflet explains how you can do this by agreeing that we can take a sample of your blood, saliva, urine, sweat or faeces .

Before you decide we would like you to understand why the research is being done 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. Please take time to read the following information carefully and to decide whether or not you wish to take part. Please ask us if there is anything that is not clear to you, or if you would like any further information.

Why am I being asked to take part in this study?

Imperial College London and Imperial College Healthcare NHS Trust are involved in research to investigate the cause of disease. We ask all of our patients who are providing samples as part of their care pathway either to donate either an extra sample or to permit us to use any left-over sample for research. We also need samples from healthy volunteers or from patients attending screening clinics so that we can look for differences in blood, saliva or urine samples from patients and healthy controls.

Who will be carrying out the research?

Your sample may be used by researchers based in academic institutions, the NHS or commercial companies worldwide.

All projects will be reviewed independently before being allowed to use your tissue.

What do I have to do?

Simply sign a consent form and giving a sample (e.g. blood, urine, saliva, sweat or faeces). Your sample will not be labelled with any identifier that would enable a researcher to know who you are.

Will the tissue be tested for (genetic) inherited disorders?

Your blood sample may be tested for inherited disorders. It is now possible to assess biological samples for genetic factors affecting disease. All samples are strictly de-identified. The Tissue Bank will not disclose information about your genetic make up in any way that could affect you or your family.

Does this affect my future medical care?

You are under no obligation to enter this study. If you allow us to take a blood sample for research, and you change your mind at any point, you can withdraw your sample from the project. However, some of your sample may already have been used for research. Giving this sample would not in any way affect any future medical treatment that you may require.

Participation in this study is unlikely to have direct benefits for you, though it may be of benefit to patients in the future.

Are there any possible side effects?

You may have some discomfort from the blood sample collection. You do not have to undergo any other extra procedures apart from answering a few basic questions as part of the study.

We will not disclose any information about you to any third party such as insurance companies and will keep all the information we have about you strictly confidential at all times.

Under the General Data Protection Regulations 2016 you are entitled to see what is recorded about you by applying to the Manager of the Imperial College Healthcare Tissue Bank, 11L03 Charing Cross Hospital, Fulham Palace Road, London W6 8RF. Tel 0203 311 7173, email: tissuebank@imperial.ac.uk.

What happens if I change my mind?

You may withdraw your consent by writing to the Tissue Bank Manager at the address above at any point and any remaining blood sample or data we have collected about you will be destroyed.

What will happen to the results of studies using my sample?

Research studies usually take several years to complete. The results from these studies will be used to improve treatment and care of patients in the future. Results will be published as appropriate in scientific papers and magazines and regular updates of research in progress, research results and other relevant information will be published on Imperial College London's website www.imperial.ac.uk.

All information will be anonymised and therefore you will not be identified in any publication.

Who funds this study?

This is a research project run by Imperial College Academic Health Science Centre, and supported by funds from funds provided by the UK government.

Who has approved this study?

The Research Ethics Committee for Wales has approved and will regularly review this project. You can contact the Research Ethics Committee at <http://www.hra.nhs.uk/news/rec/wales-rec-3/> or write to: Health and Care Research Wales Support Centre, Castlebridge 4, 15-19 Cowbridge Road East, Cardiff, CF11 9AB

If you have any further questions, please contact the person whose information is given below.

ICHTB Manager
Imperial College Healthcare Tissue Bank,
11L03 Charing Cross Hospital,
Fulham Palace Road, London W6 8RF.
Tel 0203 311 7173
email: tissuebank@imperial.ac.uk

Imperial College Healthcare Tissue Bank Donor Consent Form

Donor Identification Number for this study.....

To confirm agreement with each of the statements below, please initial in the box.

- 1. I confirm that I have read, understood and have had time to consider the information sheet dated 10/5/18 (version number 4) for the above study and have had the opportunity to ask questions.
- 2. I understand that my participation is voluntary and will not affect any future medical treatment or legal rights in any way.
- 3. I understand, and agree to, data relating to my donated samples being stored electronically.
- 4. I confirm agreement to take part in the above study.

Name of donor..... Date.....

Signature.....

Name of person taking consent Date.....

Signature..... OR

Researcher.....

Date..... Signature.....