

UCL Eastman Biobank for Studying Health and Disease**VOLUNTEER INFORMATION SHEET****Why have I been asked to read this document?**

The UCL Eastman Biobank for Studying Health and Disease Research based at the UCL Eastman Dental Institute, is interested in researching human disease and the normal functioning of the human body in order to try and find ways of better diagnosing and treating diseases. Hence, we want to try and recruit as many volunteers to donate saliva, plaque or even blood as such samples are valuable as experimental controls.

Am I being asked to take part because I am ill?

No. We are interested in involving healthy participants as this allows us to learn more about the impact that environmental and genetic factors have on the development of disease. The UCL Eastman Biobank does not carry out diagnostic testing on research samples.

What is the UCL Eastman Biobank for Studying Health and Disease?

The biobank is a collection of human material including saliva, plaque, teeth and other normal and diseased tissue from patients attending the Eastman Dental Hospital. Samples from the biobank are used in ethically approved research.

What is the purpose of the UCL Eastman Biobank?

The purpose of the biobank is to have tissue available, now and in the future, for research projects investigating oral and human disease and the normal functioning of the human body. The biobank will primarily be for the use of scientists conducting research at the UCL Eastman Dental Institute, however potentially it could be used by scientists working in or outside the UK or, in the public or private sector. Only projects that fall under the described remit of the Biobank will be approved.

Do I have to take part?

No. Whatever your decision, it will not affect your legal rights or any treatment or care you receive in this or any other hospital, now or in the future.

What will it involve if I decide to take part?

You will be asked to sign a consent form that allows donation of saliva, plaque or sometimes blood (up to 50ml or 10 teaspoons) to be taken for research. All samples will be collected by appointment at a time convenient for you. We may ask for samples on a number of occasions, but you may refuse to donate at any time without giving a reason.

What are the advantages and disadvantages of taking part?

There are potentially no advantages to you if you participate in research but it may help others in the future. You will not receive a financial reward. Any donated sample is considered a 'gift' to the biobank..

Will my information be kept confidential?

Yes. All information about you and your samples will be treated with the strictest confidence. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised.

All samples will be coded so that the researchers will not know your identity when they are working on your sample or analyzing results obtained from this. Results from genetic studies will be placed on a

database to which only authorised individuals have access. Before having access to your samples researchers have to agree to conditions which safeguard your confidentiality. You will not be informed of the results of genetic test and donating saliva, blood or plaque will have no impact on your medical insurance.

What if there is a problem or I require further information?

If at any time you would like further information or you have concerns about this research you can email us on eastmanbiobank@ucl.ac.uk and we will try to answer your question or will arrange for you to speak to an appropriate person.

Normal NHS complaints procedures will apply.

What will happen if I do not want to carry on with the study?

You are free to withdraw your consent at any time. This means that any of your samples being held in the biobank will be destroyed. Samples will also be recalled from studies where they are in use and destroyed. You do not have to give a reason for changing your mind. However, if the data has already been used it is not always possible to recall it.

What will happen to any samples that I give?

Your samples will be used in a variety of studies and may include detailed analysis of your DNA to compare healthy DNA with the abnormal DNA found in patients with various diseases, or analysis of the bacteria and other organisms found in your mouth. Samples and data may be given for research purposes to other approved researchers around the world.

Who is organizing and funding the UCL Biobank for Studying Health and Disease?

The biobank is overseen by the Research & Development Unit of UCL and UCLH. The cost of operating the biobank will be funded by UCL Eastman Dental Institute.

Who has reviewed the project?

The UCL Eastman Biobank has been given a favourable ethics opinion for conduct in the NHS by the NRES Committee Yorkshire and the Humber - Leeds East

Many thanks for taking the time to read this information.