

UCL Eastman Biobank for Studying Health and Disease

PARENT/GUARDIAN INFORMATION SHEET

Why have I been asked to read this document?

We are inviting potential donors to donate tissue and provide access to their clinical notes and imaging to the UCL Biobank for Studying Health and Disease.

Please read the following information carefully and discuss it with others if you and your child wish. Please ask us if there is anything that is not clear or if you and your child would like more information.

Why do we want to study your child's notes and imaging (x-rays and scans)?

Research will add to our overall understanding of human and dental diseases, and may help to design new ways to diagnose and treat disease.

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

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

What is the purpose of the UCL Biobank for Studying Health and Disease?

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 the UK or, in the public sector but not for commercial research. Only projects that fall under the described remit of the Biobank will be approved.

Does my child have to take part?

No. Whatever your child's decision, it will not affect any treatment or care your child receives in this or any other hospital, now or in the future.

What will it involve if I decide to permit my child take part?

On behalf of your child, you will be asked to sign a consent form:

- that allows clinical information to be extracted from your child's notes and imaging (x-rays and scans) from the Eastman Dental Hospital or University College London Hospital NHS trust (UCLH);
- that allows your child's data to be stored on a secure database in a coded/anonymised form;
- that allows storing a small piece of tissue eg a tooth, that is surplus to diagnostic requirements, for research projects including research on new therapies for managing dental disease;
- that allows collection of saliva, blood or plaque specimens for research projects including genetic research. Genetic analysis of your child's saliva often explains why certain diseases develop.

Additional tissue purely for research purposes is not removed at any time.

All these samples will be collected when your child visits his/her hospital. The saliva sample is taken by gently stroking the inside of your child's cheek with a cotton swab. The plaque sample is taken by rubbing a cotton swab over your child's gums and teeth.

Blood sample will be drawn your child's arm by a trained clinician or nurse. Firstly, we will examine and place a cuff on your child's arm to maintain a small amount of pressure. We will then find a suitable vein and clean it with an antiseptic sponge, and subsequently insert a needle in your child's arm which will collect your blood into a blood tube. Your child should not feel any discomfort or pain. This usually takes less than one minute. The needle will be removed and a sterile dressing applied to your child's arm.

We may ask for any of the above samples on more than one occasion but you can refuse at any time without giving a reason and without your child's medical care being affected.

What are the advantages and disadvantages of my child taking part?

There are potentially no advantages to your child if they participate in research but it may help others in the future. Your child will not receive a financial reward. Donated tissue is considered to be a 'gift' to the biobank.

Will my child's information be kept confidential?

Yes. All information about your child and his/her tissue samples will be treated with the strictest confidence. All information about your child would be coded so that it cannot be traced back to your child by the researcher. Results from genetic studies will be placed on a database to which only authorised individuals have access. Before having access to your child's clinical information and/or tissue samples, researchers must agree to conditions which safeguard your child's confidentiality.

Are my child and I going to receive feedback on the sample(s) my child donated?

We do not expect significant health-related findings from the studies which are approved by the UCL Eastman Biobank to use your donated teeth, plaque, saliva or blood. You and your child will therefore not be informed of the test results including genetic tests. Donating saliva, blood or plaque will have no impact on your medical insurance.

Family members

It is sometimes useful to have saliva, plaque or even blood samples from family members as this allows us to study the impact of genetic and environmental factors on the development of a disease. Therefore in some instances we may ask you to consent to allow us to contact your child's family members (parents/grandparents/cousins etc). You will also be given the Information Sheets to pass on to your child's relatives.

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

If you and your child would like further information or you have concerns about this research at any time you can:

- discuss it with your child's dentist or nurse
- email us on eastmanbiobank@ucl.ac.uk, we will try to answer your and your child's questions
- Normal NHS complaints procedures will apply.

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

You and your child are free to withdraw your consent at any time. This means that researchers will no longer be able to access any of your child's notes and images, and your child's tissue samples in the biobank will be destroyed. You and your child 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 my child gives?

Your child's samples will be used in a variety of studies and may include detailed analysis of your child's 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 in UK.

What will happen to the results of the study?

The results of our research will be published on our website <https://www.ucl.ac.uk/eastman/research/departments/clinical-research/biobank>, in dental or medical journals.

Who is organizing and funding 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 is funded by UCL Eastman Dental Institute.

Who has reviewed the project?

The UCL Biobank for Studying Health and Disease 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.