

RJAH Biobank for Studying Health and Disease

Patient Information Sheet for Children 11-15 Years Old

Why have I been asked to read this document?

We are asking if you would like to take part in a research project to help us better understand diseases. Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk about it with your family, friends, doctor or nurse if you want to.

Why are we doing this research?

We are doing this research to gain a better understanding of the processes involved in human disease and the normal functioning of the human body.

The RJAH Biobank for Studying Health and Disease is a source of clinical information and tissue for a number of research projects that study human disease and the normal functioning of the human body. The research we do could help develop new methods of diagnosis and treatment.

Why have I been chosen?

You have been invited to join our study because you are being seen by doctors at the Robert Jones and Agnes Hunt Orthopaedic Hospital (RJAH) NHS Foundation Trust.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If at any time you don't want to do the research anymore, just tell a parent or guardian, or doctor or nurse. Nobody will be upset.

What will I be asked to do?

When you have an operation, a little bit of your tissue is normally removed in order to provide a tissue diagnosis of your condition. If you allow us, we will keep a small part of that tissue that would have normally been thrown away, to use it for our research. There is no need to take any extra tissue from you during surgery, and only tissue that would otherwise be thrown away is kept for research. You would have exactly the same operation as if you had decided not to take part in the study.

We may also ask for samples of blood. We only take blood samples if you are having an operation, or if it is being taken as part of your normal treatment. If you are not undergoing surgery and blood is not being taken part of your routine treatment, then we will not take blood from you. We may also ask for urine samples, saliva, sputum and/or faecal specimens.

Will joining in help me?

We cannot promise the study will help you but the information we get might help treat others with various diseases and conditions in the future. Donated tissue is considered to be a 'gift' to the Biobank.

Is there anything to be worried about if I take part?

No, there are no added risks to the treatment or investigation that you are having for your condition.

What if there is a problem or something goes wrong?

If there is a problem and you wish to complain, or have any worries about this study then you can talk to a parent or guardian, your doctor, or people that work in our hospital, who will help you with any problems you have.

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Will anyone else know I am taking part in this study?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. We will only send out information that has your name and address removed.

What will happen to the results of the study?

The results of our research will add to our overall understanding of human disease and the normal functioning of the human body. This information may help design new ways to diagnose or treat diseases and other conditions in the future.

What will happen if new information becomes available?

We do not expect to report the results from the research on your samples to you although very exceptionally a finding might be reported to your doctor if it were considered that it may have an impact on your clinical treatment, and they would discuss this with you.

Who is organising and funding the research?

The RJAH Biobank for Studying Health and Disease is overseen by the Joint Research Office of RJAH. The cost of operating the Biobank will be funded by sponsors.

Please ask any questions if you need to.

If you have any questions that the person who looks after you cannot answer, you can ask them to contact the Biobank Manager on 01691 404120, who will try to answer your question or will arrange for you to speak to an appropriate person.

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

You can change your mind to be involved in the research at any time. This means that researchers will no longer be able to access any of your notes and images, and your tissue samples in the Biobank will be destroyed. You do not have to give a reason for changing your mind. However, if some data have already been used it is not always possible to recall it.

To withdraw your consent, please ask the person who looks after you to contact the Biobank Manager on 01691 404120 or write to us at RJAH Biobank for Studying Health and Disease, Department of Histopathology, Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust, Oswestry, SY10 7AG..

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. The RJAH Biobank for Studying Health and Disease has been given a favourable ethics opinion from the National Research Ethics Service (NRES) Committee, Yorkshire & the Humber – Leeds East Research Ethics Committee. The REC number is 17/YH/0108.

Thank you very much for reading this information.