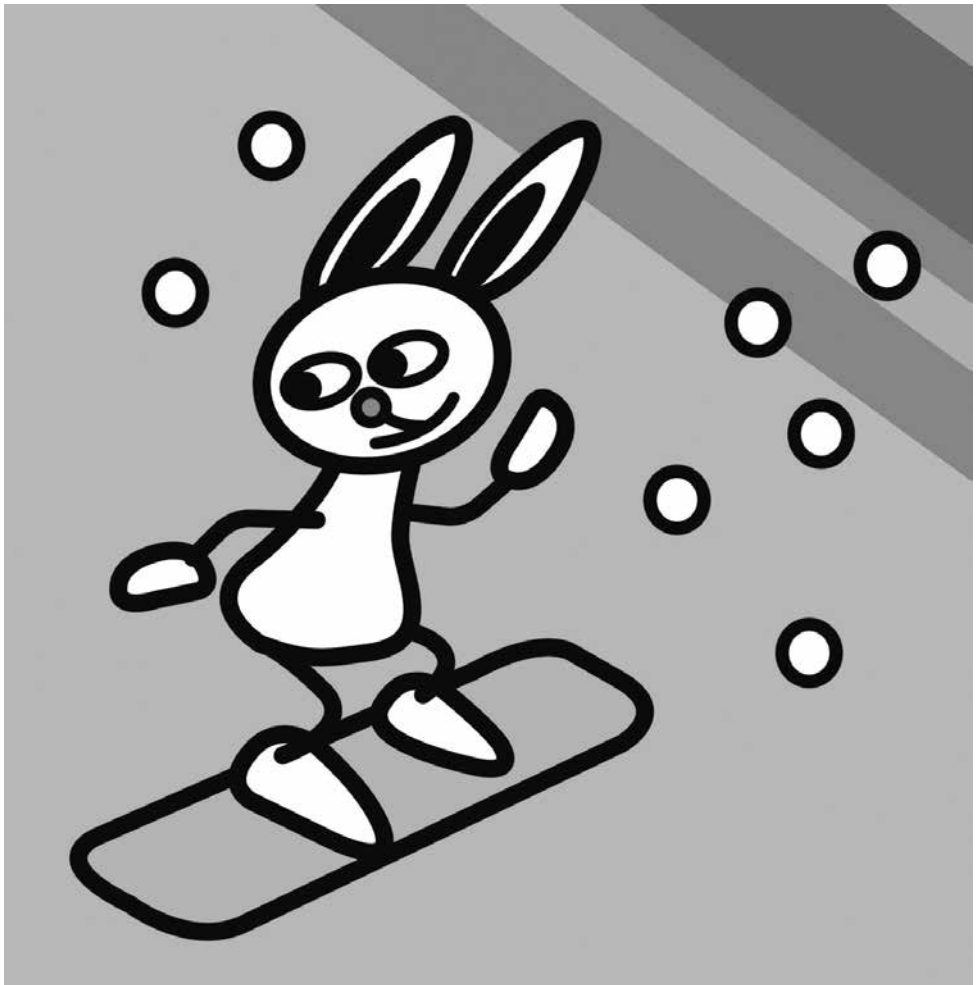


Research in the Oxford Children's Hospital

Information for patients/carers





Thank you for taking the time to read this short leaflet about research in the Children's Hospital.

We are the **Paediatric Research Team**. Our aim is to give the best possible care to you and your child whilst you are in the Oxford Children's Hospital.

There is good evidence to show that hospitals actively involved in clinical research have **better clinical outcomes for patients**.

For this reason we are passionate about clinical research. We believe we should offer every child in the hospital the opportunity to be involved in research.

This leaflet explains what clinical research is and why we do it – allowing you to make informed decisions for your child and your family.

What is research?



Research is a structured process leading to new information about a treatment, test or condition. This new information can be used in many different ways. Some examples of positive outcomes from research include:

- 1.** a new drug or therapy that treats a known condition better than a previous one
- 2.** a new test that allows us to give you more accurate information about your child's condition
- 3.** a new device that would allow us to treat your child more effectively.

Why do we do research involving children?

Children do not always have the same diseases and conditions as adults, or they may experience them in a different way. The only way to understand a childhood condition is to research that condition in children.

Medical research in children leads to innovations in healthcare that can improve their health and quality of life.

The way children process and respond to medication may vary compared to adults, and according to the age of the child. Research is necessary to find the most effective dose of many medicines given to children.

Who will conduct the research?



As well as your child's own doctors and nurses there is a dedicated Paediatric Research Team within the Children's Hospital.

Our team is made up of doctors, nurses and administrative staff who are experts in how to perform studies, and how to link up with other hospitals, as higher numbers of patients improve the accuracy of research.

Some of these studies may involve hospitals worldwide.

Will my child benefit from research?

Your child may not benefit directly from the clinical study, but other children in the future may be helped by the information gained through your child's participation in the study, whatever the findings are.

Although your child may not benefit directly, there is good evidence to show that hospitals actively involved in clinical research have better clinical outcomes for patients.

How will safety be monitored?



Every piece of research that is conducted on patients within the NHS must have approval from an ethics committee. Their role is to protect the rights and wellbeing of patients. This includes all the research that we conduct at Oxford Children's Hospital.

Our research will only gain approval for conduct within the NHS if the child's interests are shown to be the most important part of the study. The research must have the potential to improve human health and wellbeing.

If the research is testing a new way of treating a condition, children taking part will be very closely monitored for any unwanted effects. This is done by a group of people independent from the trial and concerned just with safety.

What if I don't want my child to be involved?

The decision to take part in research is always voluntary. Your child will receive excellent care whether you decide to participate or not. You are also free to withdraw your child from any study at any time, and you do **not** have to provide a reason.

If you do agree to participate in a research study, the team will check regularly that you are happy to remain in the study.

Finding out about research projects relevant to your child

If there is a study for which your child is eligible, you will be approached by a member of the research team, together with your clinical team, to have an initial discussion.

They will explain the study and what it involves, and give you a chance to ask questions.

Most studies allow some time to make a decision, but some (involving treatments in very ill children) may require you to make a decision quickly.

We are very aware that this is a stressful time for you, and will give you as long as possible to decide.

If you and your child agree to take part in a research study you will be asked to sign a consent form.

If your child is under 16 they can sign the form too, but a parent or guardian's signature is essential.

Results of research trials

The results of most trials are published in the form of an article in a scientific journal.

As there is much work to be done collecting and analysing data, trials are often published several years after patients have been recruited.

Sometimes it takes several years to recruit all the patients needed.

Who to speak to for more information

If your child is enrolled in a research study you will be given direct lines of contact to the research team involved.

For general information about research in the Oxford Children's Hospital, please talk to your clinical team or to us in the Paediatric Research Team:

Telephone: 01865 231 729

Email: childrensresearch@paediatrics.ox.ac.uk

For more information about research at Oxford University Hospitals, please visit:

www.ouh.nhs.uk/research

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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