



NON-STOP: NON-Surgical Treatment Of Perthes' Disease

Chief Investigator(s):

Professor Anthony Redmond and Mr Adam Galloway

INFORMATION SHEET FOR PARENT/GUARDIAN

BACKGROUND

The NON-STOP study is aiming to test a new app to help children with Perthes' Disease and their families manage their condition. Previously you agreed we could contact you to discuss taking part in a research study. The aim of the study is to monitor how the app is used over a six-week period.

This document will explain in more detail what the study will include. **Please take time to read this and feel free to discuss with others if you wish.**

WHAT HAPPENS IF I SAY YES?

If you and your child decide to take part in the study, we will ask you to reply to the email that contained this sheet, with an 'agreement statement' as described, this will act as consent to take part in the study. It will say that you have read this information sheet, had time to decide whether to be involved and agree to take part. We will then arrange to set you up with the NON-STOP app and give you instructions on how to use it over the six weeks.

At the beginning of the study, you'll be asked to provide some information relating to your child's condition, then you'll be instructed to download the app. During the six-week period you'll use the app at home with your child. The app includes information about Perthes' Disease as well as instructional videos for children on how to complete their physiotherapy exercises.

After the six weeks have passed, you'll be asked to provide some more information about your child's condition again and instructed that this is the end of the study period. At this point you'll stop using the app.

DO I HAVE TO TAKE PART?

No. It is completely up to you whether you would like to take part, and you do not need to decide straight away. You are also free to change your mind and withdraw from the study at any point. It is also absolutely fine if your child doesn't want to take part. Whether you/your child decide to take part or not will not affect the clinical care that your child receives.

ARE THERE ANY BENEFITS TO TAKING PART?

There are no specific benefits to taking part in the study. However you will have the opportunity to use a new treatment approach in the care of Perthes' Disease. Also, you'd be contributing to a study that could change the way we care for children with Perthes' Disease.



ARE THERE ANY RISKS IN TAKING PART?

Similar to the benefits, there are no specific risks in taking part. There is a time-burden involved with taking part, but we hope that this is minimal and that you can use the app when you have time.

WILL MY INFORMATION BE KEPT CONFIDENTIAL?

Yes. Your contact details [name, email address and phone number] will be kept in password-protected files. Only the research study team will have access to this. After the study you will be sent a summary of the research study and then your details will be destroyed.

If you have any concerns about data privacy during the study you can email dpo@leeds.ac.uk

Alternatively, visit https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2020/08/My_data_and_research.pdf , <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf> or HRA website www.hra.nhs.uk/information-about-patients/ for more information on data privacy.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

You will receive a summary of the study once we have analysed the results. There will be reports published in medical journals and at conferences, that will be available to you if you wish. We will also provide a summary of the research findings on social media pages and relevant Perthes' Disease charity pages. This piece of research is being done as part of a PhD; the results will contribute to the thesis written as part of this.

WHO HAS REVIEWED THIS STUDY?

Every piece of research that takes place in the NHS is reviewed by a group of specialists called a Research Ethics Committee. This is to make sure that any research conducted is done with the least risk of burden possible for the participants. This study has been reviewed by **[insert committee details]** and deemed safe to proceed.

WHAT IF THERE IS A PROBLEM?

This study is sponsored by the University of Leeds. If you wish to discuss any aspect of the research study then you can contact the Chief Investigator, Professor Anthony Redmond at a.redmond@leeds.ac.uk.

If you wish to withdraw at any point during the study, we can destroy the information you have provided.

FURTHER INFORMATION AND CONTACT DETAILS

If there are any other questions or concerns about the study, please contact Adam Galloway at a.galloway@leeds.ac.uk

Thank you for taking the time to read this information and consider taking part in our study.