

Chief Investigator(s):Professor Anthony Redmond and Mr Adam Galloway

INFORMATION SHEET FOR PARENT/GUARDIAN

BACKGROUND

You have been invited to take part in the NON-STOP study because your child has Perthes' Disease. The NON-STOP study is aiming to test a new app to help children with Perthes' Disease and their families, such as yourself, 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 still have access to the app, but we will stop collecting data.

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.

HOW WILL WE USE INFORMATION FROM YOU?

We will need to use information from you for this research project. This information will include contact details [name, email address and phone number]. People will use this information to do the research or to check your records to make sure that the research is being done properly.

We will keep all information about you safe and secure. Your details will be kept in password-protected files. Only the research study team will have access to this. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. After the study you will be sent a summary of the research study and then your details will be destroyed.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

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> 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?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Edgbaston Research Ethics Committee.

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. For complaints, contact your local PALS on _____



You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

FURTHER INFORMATION AND CONTACT DETAILS

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team by sending an email to a.galloway@leeds.ac.uk

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