UNIVERSITY OF LEEDS

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 took part in the study to test this app and agreed we could contact you to discuss you and your child taking part in a further study as part of the app-testing. The aim of the study is to ask a small group of people their thoughts on the app and experiences of using it.

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 decide to take part, we will ask you to reply to the email that contained this sheet, with an 'agreement statement' as described, this will act as consent for you and your child 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. You and your child will then be invited to a face-to-face group interview called a focus group. There will be a group of 4-5 children in one group discussing their experiences of using the NON-STOP app. After this group has completed, a group of 4-5 adults will discuss their experiences of using the NON-STOP app.

The focus group will take between 30-90 minutes in total and will be recorded using a small recording device so that the researcher can listen to your answers again at a later time.

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. 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 interview. However sometimes people feel there is a benefit to sharing their experiences and feel that being involved in research studies like this can help contribute to a better understanding of the condition. This might be particularly important in a condition like Perthes' Disease where we don't know an awful lot about the experiences of those most involved.

ARE THERE ANY RISKS IN TAKING PART?

Similar to the benefits, there are no specific risks in taking part. It is possible that having to recall previous experiences could bring back memories of something potentially upsetting. The research team will be able provide support however, and offer the chance to take a break or, if needed, stop the focus group at any point.

In the rare occasion there are any safeguarding issues, confidential information may need to be shared with your existing medical team.

We appreciate that it can be time-consuming to take part in research, and because of this, we have funding to reimburse you and your child for your time and have a childcare allowance if this makes it more realistic for you to take part. In line with NIHR guidance this will be a maximum of £50.

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. A company affiliated with the university will type up the recording of the focus group (removing names/details that might identify your family) and we will keep these for ten years after the study has finished. This is in line with the laws on doing research, after this, they will be destroyed as well. We might use direct quotes from what you say in the interview but we won't name you or make it so anyone would know it was you who said it.

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

Alternatively, you can 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?

As mentioned previously, you will receive a summary of the study once we have analysed the focus group. There will be reports published in medical journals and at conferences, that will be available to you if you wish, but these will not name any participants. 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.