



UNIVERSITY OF LEEDS

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

Chief Investigator: Adam Galloway

PARTICIPANT INFORMATION SHEET

BACKGROUND

There is currently no standardised treatment for children with Perthes' Disease, and we need expert-opinion to achieve consensus on how best to treat this group of children in the UK. The NON-STOP Delphi study is designed to do just that, and we need your help to improve the care for patients with Perthes' Disease and their families.

Using Delphi methods, a team including myself, Prof Dan Perry and Mr Colin Holton and others plan to use expert opinion to develop recommendations for the Non-Surgical Treatment of Perthes' Disease (NON-STOP).

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

This study is being completed as part of a HEE/NIHR Clinical Doctoral Research Fellowship. Project ID: NIHR301228

WHAT HAPPENS IF I SAY YES?

If you are happy to take part in the consensus study, continue to the next page which includes an 'agreement statement'. It says that you have read this information sheet, had time to decide whether to be involved and agree to take part in the Delphi study. Once this has been completed, the next page is the start of the Delphi study survey.

You are invited to complete an online survey, that will take around 15-20 minutes to complete on two occasions around 2-3 weeks apart. It is important that you complete both surveys so that your data contributes to the final recommendations from the study.

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 for more information about data privacy.

DO I HAVE TO TAKE PART?

No. It is completely up to you if 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, without giving a reason. Your clinical service will not be informed of your participation.



ARE THERE ANY BENEFITS TO TAKING PART?

There are no specific personal benefits to taking part in the study. People often feel there is a benefit to sharing their experiences and opinions. They also feel that being involved in research can help contribute to the understanding of the condition and the care that children receive.

ARE THERE ANY RISKS TO TAKING PART?

There are no identified risks to taking part.

WILL MY INFORMATION BE KEPT CONFIDENTIAL?

Yes. Your contact details [name, email address and phone number] will be kept electronically in password-protected files until the study has finished. At this point you will be sent a summary of the research study and then your details will be destroyed.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this study will be shared using channels such as paediatric orthopaedic specialist professional groups such as British Society of Children's Orthopaedic Surgery and the Association of Paediatric Chartered Physiotherapists. It will also be shared with children with Perthes' Disease and their families using existing links with relevant charities/groups.

As part of the wider PhD, the results of this study will inform NON-STOP and the overall care of children with Perthes' Disease and their families and inform the design and development of a digital self-management intervention.

WHO HAS REVIEWED THIS STUDY?

This study has been assessed by the University of Leeds, School of Medicine Research Ethics Committee (insert specific reference after approval). This is to make sure that any research conducted is done with the least risk of burden possible to the participants.

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, Adam Galloway at a.galloway@leeds.ac.uk.

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.