Summary of evidence for Non-Surgical Treatment of Perthes' (NON-STOP) Delphi study

Thank you for considering taking part in the Delphi study to achieve clinical consensus on NON-STOP. This document provides a brief summary of the available evidence that is relevant to this study as well as links to full texts where possible. The aim is to provide some clinical context prior to the start of the survey that will follow, which includes statements around NON-STOP for you to vote on, displaying your level of agreement/disagreement. The domains within the survey have been designed based on the evidence provided, as well as input from key stakeholders including specialist clinicians and patient/public involvement.

1. *Qualitative study of key stakeholders (unpublished work)*

This study is in now complete and in the write-up stage. It involved interviews with clinicians and children with Perthes' Disease and their families, the questions aimed to explore their experiences of NON-STOP as well as their thoughts on what future care should look like including ideas on a digital self-management intervention (an app). A summary of the responses that arose are:

- Clinicians and child/family dyads need consistent advice based on evidence.
- Long and short-term goals were discussed i.e., treatment that impacts both radiological outcome at skeletal maturity and function i.e., pain, activity levels. With the focus from both being quality of life in the first instance.
- The idea of an app well received as a concept by clinicians and child/family dyads.
- An app could provide a step towards consensus/agreement on treatment and a reduction in variation of care.

2. *Systematic review of NON-STOP (https://tinyurl.com/NON-STOPSR)*

This systematic review compared the effectiveness of non-surgical interventions against one another. It looked at a range of interventions including active observation, physiotherapy, bracing/casting and activity modification/weightbearing change. There was no robust evidence to support one NON-STOP compared to another with majority of studies having significant issues with methodological quality and bias. Some studies showed improvement in domains like range of motion and strength with physiotherapy input, however it did not correlate with radiological changes at skeletal maturity and outcomes such as quality of life and function were not measured. Overall the paper concludes that more research in NON-STOP is needed.

3. *Case review: variation of care in Perthes' Disease (https://tinyurl.com/NON-STOPCR)*

A case review looking at five centres in the UK demonstrated widespread variation of care in the UK when assessing things such as advice on pain relief and activity modification, input from physiotherapy locally or regionally and how often they are seen by orthopaedic specialists (physiotherapy and medical).

4. *The BOSS Study results (https://tinyurl.com/BOSSresults)*

The British Orthopaedic Surgery Surveillance study provided data on incidence and rate of surgical intervention in all but one hospital in the UK. It showed that despite a third of patients receiving surgery, there were no evidence of improved outcomes in quality of life or Stulberg. It did however demonstrate appropriate numbers for a future randomised trial, which this Delphi study would inform for the conservative management arm.

5. *Herring, 2004 (https://pubmed.ncbi.nlm.nih.gov/15466720/)*

One of only two prospective cohort studies, studied surgery and no surgery and found that children aged >8 years old did better with surgery however females of any age, and those aged >8 years old did worse than those younger, irrespective of gender or treatment type. Also demonstrated no significant difference in outcomes when looking at NON-STOP.

6. *Wiig, 2008 (https://pubmed.ncbi.nlm.nih.gov/18827249/)*

This prospective study suggested that children over the age of six years old at diagnosis with >50% femoral head involvement had better outcomes from surgery compared to physiotherapy or orthosis. As with the Herring study, this study relied on post-hoc analyses and therefore are at risk of type I error.

7. *Perthes' core outcome set (https://pubmed.ncbi.nlm.nih.gov/32349599/)*

This piece developed a set of outcomes to be employed in future studies in Perthes' Disease. They did so by carrying out a Delphi study with key stakeholders nationally and internationally and finished with 16 outcomes derived from 6 categories (life impact, resource use, pathophysiological manifestations, death and technical considerations). They also provided the PROMIS mobility as a valid tool in this population.