■ CHILDREN'S ORTHOPAEDICS

Clinical consensus recommendations for the non-surgical treatment of children with Perthes' disease in the UK

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Aims

The aim of this study was to produce clinical consensus recommendations about the non-surgical treatment of children with Perthes' disease. The recommendations are intended to support clinical practice in a condition for which there is no robust evidence to guide optimal care.

Methods

A two-round, modified Delphi study was conducted online. An advisory group of children's orthopaedic specialists consisting of physiotherapists, surgeons, and clinical nurse specialists designed a survey. In the first round, participants also had the opportunity to suggest new statements. The survey included statements related to 'Exercises', 'Physical activity', 'Education/information sharing', 'Input from other services', and 'Monitoring assessments'. The survey was shared with clinicians who regularly treat children with Perthes' disease in the UK using clinically relevant specialist groups and social media. A predetermined threshold of ≥ 75% for consensus was used for recommendation, with a threshold of between 70% and 75% being considered as 'points to consider'.

Results

A total of 40 participants took part in the first round, of whom 31 completed the second round. A total of 87 statements were generated by the advisory group and included in the first round, at the end of which 31 achieved consensus and were removed from the survey, and an additional four statements were generated. A total of 60 statements were included in the second round and 45 achieved the threshold for consensus from both rounds, with three achieving the threshold for 'points to consider'. The recommendations predominantly included self-management, particularly relating to advice about exercise and education for children with Perthes' disease and their families.

Conclusion

Children's orthopaedic specialists have reached consensus on recommendations for non-surgical treatment in Perthes' disease. These statements will support decisions made in clinical practice and act as a foundation to support clinicians in the absence of robust evidence. The dissemination of these findings and the best way of delivering this care needs careful consideration, which we will continue to explore.

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Introduction

Perthes' disease causes considerable pain, destruction of the hip, and limited function as a result of avascular necrosis of the developing femoral head.[1] The aetiology is unknown and the incidence varies according to geographical location. The incidence in the UK is 5.7 per 100,000 children; however, there are marked differences between the incidence in the northwest and the south of England (9.5 and 4.6 per 100,000, respectively). There is a strong association between the disease and worsening socioeconomic deprivation.[2,3]

The aim of management, surgical or non-surgical, is to optimize the congruency of the hip

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Table I. Domains within the Delphi study.

Domain	Topics covered
Exercises	Strengthening exercises (early and late stage) ROM exercises (early and late stage) Water-based exercises Functional ability exercises Who, when, and where to do exercises
Physical activity	Recreational activities (early and late stage) Activity modification
Education/information sharing	Understanding Perthes' disease Pain management Weight management and nutrition Mental wellbeing
Input from other services	Referral to an orthopaedic surgeon Referral to physiotherapy Multidisciplinary team input Communication between children/families and clinicians School support
Monitoring assessments	ROM measurement Outcome measures Orthopaedic follow-up

ROM, range of motion.

Table II. Professions of those who participated in the first and second rounds.

Profession	First round (n = 40)	Second round (n = 31)
Physiotherapist, n (%)	22 (55)	19 (61)
Orthopaedic surgeon, n (%)	17 (43)	11 (36)
Clinical nurse specialist, n (%)	1 (2)	1 (3)

and the spherical growth of the femoral head. There is also a widespread variation of management in the UK.[4] The recent British Orthopaedic Surveillance Study (BOSS) provided insight into the management of Perthes' disease in 143 of the 144 NHS hospitals treating children's hip disease in the UK.[3] Definitive non-surgical treatment remains the most common form of management. There is, however, little robust evidence or agreement about the form of treatment, its timing, or duration.[5] The British Society of Children's Orthopaedic Surgery (BSCOS) and the James Lind Alliance have identified Perthes' disease as a research priority in an attempt to establish the optimal treatment.[6,7] Our recent qualitative study demonstrated a strong desire from clinicians, and children with the disease and their families, for a consensus in the treatment of Perthes' disease to be established.[8]

Consensus-generating studies allow the opinion of relevant experts to deliver recommendations in the absence of robust evidence. Several well-described methodologies for establishing consensus are available, with a range of strengths and weaknesses of each.[9] The Delphi method was selected because the electronic and remote capability allowed experts from different clinical settings and backgrounds in many geographical locations to participate.[10]

The aim was to develop a consensus of clinical recommendations for the non-surgical management of children with Perthes' disease.

Methods

This modified Delphi study was completed using online surveys. In order to ensure that the results reflected the views of appropriate stakeholders,[11] participants were clinical specialists in the treatment of children's orthopaedic diseases, including physiotherapists, orthopaedic surgeons, and clinical nurse specialists. Recruitment took place primarily from two professional body special interest group mailing lists (BSCOS and Association of Paediatric Chartered Physiotherapists (APCP)). Invitations to participate were emailed to all members of each group. Social media was used to maximize awareness. The invitations included a link to the study, which guided participants through a consent process.

Participants firstly assessed their own eligibility by confirming that they: 1) worked in a clinical setting that manages children with Perthes' disease at least once a week; 2) had at least two years' experience of treating these children; and 3) had access to the relevant technology, including a digital device capable of completing the online survey and email.

Careful sampling was used to ensure a heterogeneous sample of specialists in the patient population, this was done using a purposive sampling approach.[12] We aimed to recruit between 12 and 15 surgeons or clinical nurse specialists, and between 12 and 15 physiotherapists, with a total of between 24 and 30 clinicians. Due to the nature of the Delphi methodology, it is not possible to calculate optimal sample sizes and therefore we used a pragmatic approach based on the available literature. Nair et al[13] highlighted that Delphi panels must include an adequate number of participants and, while that can be several hundred, it should be at least ten. Our recruitment target, therefore, was deemed likely to result in sufficient responses to meet the aims of the study.[14]

A survey advisory group, consisting of physiotherapists, orthopaedic surgeons, and clinical nurse specialists with extensive experience of treating children with Perthes'

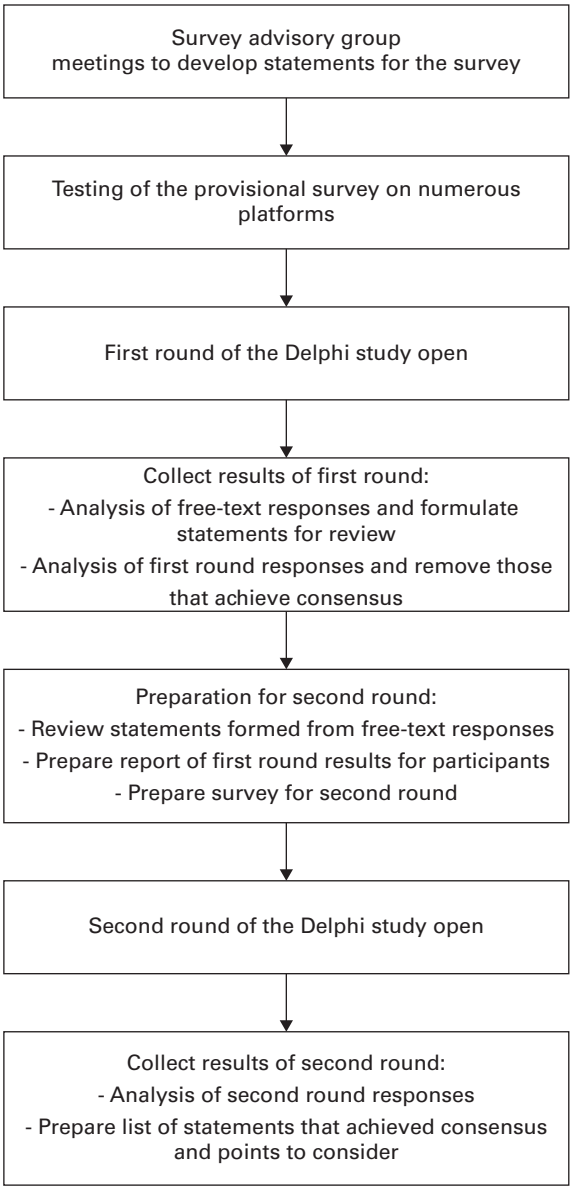

Fig. 1

Flow chart showing Delphi process.

disease, contributed to the design of the survey. They met three times and corresponded via email to create the survey. The group had an independent chair (AA) who contributed methodological expertise.

The group combined their expert opinions with a 'summary of evidence' (Supplementary Table i) to develop the survey (Table I).

One key decision by the group was the definition of the 'early' and 'late' stage of Perthes' disease. The rationale for this was that advice given to families often varies at different stages of the disease. For example, advice about weightbearing and high-impact activities, such as the use of trampolines, bouncy castles, and long-distance running, is considered more relevant to management early in the disease, as it is believed that these activities carry a risk of microdamage to the developing capital femoral epiphysis.[15,16] Any recommendations made about exercise and general activity were therefore dependent on the stage of the disease. Thus, it was decided to classify the 'early stage' as disease anywhere in the initial, sclerotic, or fragmentation stage.[17] The stage was classified as 'late' if there was reossification or healing of the epiphysis. These definitions were shared with participants completing the survey. Participants took part in two rounds of the Delphi study, and each was open for three weeks. The first round involved 87 statements about non-surgical forms of treatment.

They were initially asked to indicate their discipline (physiotherapist, nurse, or surgeon), and then to indicate their level of agreement for each statement using a five-point Likert rating scale:[18] 1) strongly agree; 2) agree; 3) neither agree nor disagree; 4) disagree; and 5) strongly disagree. Free-text boxes allowed participants to suggest new statements or clarifications to existing statements in preparation for the second round. New statements or clarifications were discussed with the advisory group, who decided the actions for the second round by agreement.

For the second round, a summary of the results from the first round, including the statements that reached consensus, was sent to the participants. These statements were removed from the second round to minimize the burden for participants. No free-text boxes were available for the second round and participants were again asked to rate the statements using the Likert scale. They were made aware of four new statements in this round.

Free-text responses from the first round were analyzed using content analysis,[19] which involved reviewing the responses and identifying content related to the domains in the survey. For example, a new statement generated via free-text responses in the first round was "children with Perthes' disease should complete regular cardiovascular exercise aiming to increase heart rate and respiratory rate (as per national guidelines)." This statement was included in the second round for assessment of consensus in the domain of 'Exercises'.

Quantitative analysis for the first round involved removing statements that achieved the predetermined level of consensus of ≥ 75% for either 'agreement' or 'disagreement'. 'Agreement' for this study was a response of 'agree' or 'strongly agree', and 'disagreement' was a response of 'disagree' or 'strongly disagree'. The same thresholds for agreement were used in the second round.

For statements in which consensus was not reached, but came close to achieving consensus, it was felt that individual clinicians may wish to consider these statements – termed 'points to consider', which were defined as any statement with 70% to < 75% in either agreement or disagreement. An overview of the process is shown in Figure 1.

Results

A total of 40 participants responded in the first round, of whom 31 responded in the second. A summary of the professional backgrounds of the participants is shown in Table II.

In total, 31 of the 87 statements in the first round reached consensus and were removed from the second round. Four statements were added in the second round as a result of

Table III. Clinical consensus recommendations for children with Perthes' disease.

#	Domain
	Exercises (n = 14 items)
1	Children with 'early stage' Perthes' disease should not participate in high impact strengthening exercises (e.g. squat-jumps, star-jumps)
2	Children with 'early stage' Perthes' disease should complete regular cardiovascular exercises aiming to increase heart rate and respiratory rate (as per national guidelines)
3	Children with 'late stage' Perthes' disease should complete hip-strengthening exercises
4	Children with 'late stage' Perthes' disease should complete trunk-strengthening exercises
5	Children with 'late stage' Perthes' disease should complete regular cardiovascular exercises aiming to increase heart rate and respiratory rate (as per national guidelines)
6	Children with 'early stage' Perthes' disease should complete hip stretches
7	Children with 'late stage' Perthes' disease should complete hip stretches
8	Children with 'late stage' Perthes' disease should complete any stretching exercise as long as they avoid discomfort
9	Children with Perthes' disease should complete water-based exercise as self-management, i.e. prescribed exercises in a local pool (not supervised by a physiotherapist)
10	Children with Perthes' disease should complete water-based exercise when land-based physiotherapy is not effective
12	Children with Perthes' disease should complete balance exercises
13	Children with Perthes' disease should receive gait education
14	Children with Perthes' disease should have advice on potential use of mobility aids
	Physical activity (n = 9 items)
1	In the 'early stages' of Perthes' disease, swimming should be encouraged
2	In the 'early stages' of Perthes' disease, contact sports (e.g. football, rugby) should be discouraged
3	In the 'early stages' of Perthes' disease, long-distance running (more than 1 to 2 miles) should be discouraged
4	In the 'early stages' of Perthes' disease, cycling should be encouraged
5	In the 'early stages' of Perthes' disease, high-impact (e.g. bouncy castles and trampolines) should be discouraged
6	In the 'late stages' of Perthes' disease, swimming should be encouraged
7	In the 'late stages' of Perthes' disease, horse riding should be encouraged
8	In the 'late stages' of Perthes' disease, cycling should be encouraged
9	Children with Perthes' disease should use a walking aid (e.g. crutches, Zimmer Frame) to modify their activities if symptoms (e.g. pain, limping, reduced activity levels) persist
	Education/information sharing (n = 13 items)
1	Clinicians should provide children/families with information regarding the disease process including the affected anatomical structures and prognosis
2	Clinicians should provide children/families with information regarding current research relating to Perthes' disease including aetiology and epidemiology
3	Clinicians should provide children/families with information regarding where additional patient and family information resources can be found (e.g. STEPS website)
4	Children with Perthes' disease should be advised to take paracetamol or equivalent for pain management
5	Children with Perthes' disease should be advised to take ibuprofen or equivalent for pain management
6	Children with Perthes' disease should not be advised to take morphine or equivalent for pain management
7	Children with Perthes' disease should be advised on pacing and activity levels
8	Children with Perthes' disease should be advised on the use of heat/cold therapy
9	Children with Perthes' disease should be provided with resources on chronic pain for persistent pain related to Perthes' disease (where general Perthes' advice is not relevant/effective)
10	Children with Perthes' disease should receive advice on lifestyle, weight management, and nutrition from a healthcare professional
11	Children with Perthes' disease should be referred to a specialist service for weight management and nutrition when clinically indicated
12	Parents of children with Perthes' disease should be given the opportunity to discuss their (or their child's) mental wellbeing with any healthcare professional
13	Children with Perthes' disease should be signposted to general mental wellbeing resources (e.g. the STEPS charity website or NHS 111 website)
	Input from other services (n = 7 items)
1	Any child with suspected Perthes' disease should be referred for specialist review by an orthopaedic surgeon
2	Any child who does not improve from a symptom/symptom management perspective should have access to an orthopaedic consultant/ equivalent
3	Children with Perthes' disease should be offered an initial assessment with a physiotherapist
4	Children with Perthes' disease should be seen by a physiotherapist until they can self-manage independently
5	Children with Perthes' disease and their families should have a means of direct communication with clinicians between appointments
6	Children with Perthes' disease and their families should be directed towards means of contacting other children with Perthes' disease and their families, i.e. peer support groups/forums
7	Children with Perthes' disease should have access to a named school support staff member
	Monitoring assessments for clinical practice (n = 2 items)
1	Children with Perthes' disease should have their ROM documented at every appointment (regardless of MDT role)

Continued

Table III. Continued

#	Domain
2	Children with Perthes' disease should have a validated quality of life assessment tool completed at initial assessment and regular intervals
	Points to consider (n = 3 items)
1	Children with 'late stage' Perthes' disease should complete knee-strengthening exercises
2	Children with Perthes' disease should be referred to a pain management service if their symptoms are not managed with medication and/or physiotherapy
3	Children with Perthes' disease should have regular reviews with an orthopaedic specialist until they reach skeletal maturity

Some statements relate to 'early stage' or 'late stage' Perthes' disease and are indicated in the statement. If there is no indication, then the statement applies to all stages of the condition.
MDT, multidisciplinary team; ROM, range of motion.

Table IV. Key statements which did not reach consensus.

#	Statement achieving 'No consensus' (n = 4 items)
1	Children with 'early stage' Perthes' disease should complete hip-strengthening exercises
2	Children with 'early stage' Perthes' disease should complete any strengthening exercise as long as they avoid discomfort
3	Children with 'late stage' Perthes' disease should complete any strengthening exercise as long as they avoid discomfort
4	Children with Perthes' disease should be seen by a physiotherapist regularly until the disease process is complete/healing is observed

free-text responses. In the second round, 14 statements achieved consensus and three were deemed to be 'a point to consider'. The 45 consensus recommendations and 'points to consider' are shown in Table III.

A total of 46 statements did not achieve consensus. Most of these related to the provision of exercise and advice about physical activity, some related to the services that may be involved with these children. Four statements of clinical relevance are described and discussed in Table IV.

Discussion

The care of children with Perthes' disease varies in different parts of the world. In 2022, McGuire et al[20] conducted an international web-based survey of more than 1,000 adults who had been treated for Perthes' disease in childhood. They reported widespread differences in whether they had received treatment such as physiotherapy, and advice about whether they should use a walking aid or modify their activities. Variation in care adversely affects these children and their families, as recently reported by Galloway et al.[8] Family members and clinicians expressed their desire for consensus after noting a general sense of disagreement. In response, this study was undertaken to address these issues by developing clinical consensus recommendations for the optimal treatment of Perthes' disease based on the opinion of experts.

The recommendations are predominantly in the domains of physical activity and the provision of exercise. The amount of physical activity and exercise for children with Perthes' disease is frequently debated in the paediatric orthopaedic community.

A recent multicentre case review highlighted the variation in the provision of physiotherapy for children with Perthes' disease in the UK.[4] The authors found that some centres do not routinely recommend physiotherapy for these children. This Delphi study achieved consensus on the need for access to physiotherapy, highlighting that children should be offered an initial assessment with a physiotherapist and reviewed until they can manage independently. This finding challenges the variation in provision of physiotherapy.

Many of the recommendations in the 'Exercises' domain are relevant to the provision of physiotherapy. The benefit of range of motion (ROM) and strengthening exercises for children with Perthes' disease has been investigated.[21] However, this study was not robust and the details of the forms of treatment were not sufficiently described to guide clinical practice. In our study, clinicians agreed that these children should complete hip stretches, irrespective of the stage of the disease. Water-based activities were recommended for children either self-directed, or as guided by a physiotherapist when land-based treatment was not effective. These findings have implications for the advice that clinicians give families, and when considering the provision of hydrotherapy. The importance of access to local swimming pools for children with Perthes' disease is also highlighted.

The authors of a previous qualitative study demonstrated the high degree of importance families place on education related to the disease, and being involved in their children's care.[8] Clinicians agreed that education about the natural history of the disease was of paramount importance in the management of Perthes' disease. There was also strong consensus (> 90%) towards support for the mental wellbeing of these children. Access to mental health services is currently difficult for children and young people in the UK. Hines et al,[22] in 2019, reported that only 46 acute hospitals (26.6%) had access to psychiatric services for children. While this may have improved, it certainly stands to reason that mental health support should be easily available for these children and their families. These could include appropriate associated organizations and online support. Clinicians could also include advice about mental wellbeing within the self-management support that they provide.

The key domains in which consensus could not be reached also included those relating to exercise and physical activity. This was somewhat expected given the broad nature of exercises and activities included in the study. The lack of consensus in many areas probably reflects the variation in care that we have previously reported.[4] For many of these domains, it seems unlikely that the nuances of therapy can be answered through

research. However, guidelines from national bodies to standardize care may be helpful to overcome the anxiety experienced by families resulting from the unneccessary differences in care.

This study focused on the non-surgical treatment of Perthes' disease. In some cases, surgery is primarily used to treat Perthes' disease, although the evidence of benefit for containment surgery compared with non-surgical treatment remains unclear.[3] Surgical approaches typically involve either a varus femoral osteotomy or an acetabular osteotomy (a shelf or Salter osteotomy).[23] Determining the consensus for surgical treatment was outside the scope of this study, although there is a recently funded UK randomized controlled trial (RCT) that will compare surgical containment and non-surgical treatment for Perthes' disease.

The strength of this study is the broad involvement of participants from the multidisciplinary team caring for these children. In the absence of RCTs, the consensus of clinical specialists is the best available approach to guide clinicians and reassure families. Participants from physiotherapy and orthopaedic surgery broadly agreed on the responses, irrespective of their discipline. There was limited clinical nurse specialist representation, despite the invaluable input that they provide in paediatric orthopaedics. Effective dissemination is vital to support clinical teams and give them the opportunity to reflect on their current service provision compared with these recommendations. Implementation of these recommendations may reduce unwarranted variations in care.

In conclusion, for the first time children's orthopaedic specialists have developed robust, expert-based consensus recommendations for the non-surgical treatment of children with Perthes' disease. The statements can be used to support decisions in the absence of robust evidence, to give confidence to clinicians and help families overcome anxiety. There is a strong theme of self-management within the recommendations, particularly relating to the advice about exercise and education for these children. The best way to deliver this care needs careful consideration, and a digital self-management tool that will include these findings is currently being developed.

Take home message

- Children's orthopaedic specialists have reached consensus on recommendations for non-surgical treatments in Perthes' disease.
- A total of 45 statements relating to exercise/physical activity advice and education can be used to guide treatment in the absence of robust evidence.
- Dissemination to support clinical implementation of these recommendations is required to reduce unnecessary variations in care, which add unwarranted anxiety for affected families.

Social media

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Supplementary material

Overview of the relevant literature that was presented to participants prior to their enrolment in this study. The aim was to summarize relevant literature relating to Perthes' disease for participants.

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D. J. Keene: Methodology, Supervision, Writing – review & editing.
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