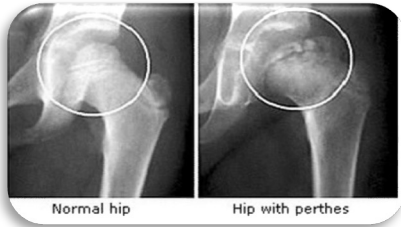


# What are the experiences of key stakeholders in NON-STOP (Non-Surgical Treatment of Perthes' Disease): A qualitative study

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## BACKGROUND



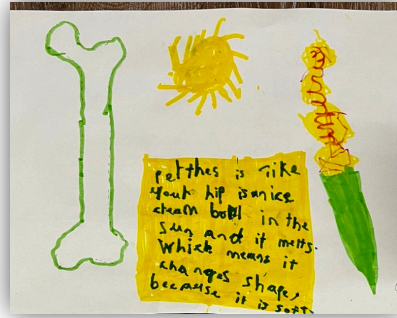
1 in 1000

Perthes' Disease is avascular necrosis of the developing femoral head. It is most typical in boys aged 4 to 9 years old.

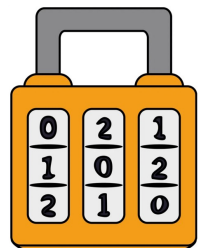
Over 100 years after being described, the experiences of key stakeholders had never been explored, until now.



## METHODS



We used video calls to interview children with Perthes' Disease and their families. We also interviewed clinicians who treat children with Perthes' Disease



Interviews followed a coding framework and an interview schedule. Both of these were informed by patient and public involvement exercises and underpinned by behavioural theory



## CLINICIANS



12 clinicians

5 consultant surgeons

7 Physiotherapists

1 Specialist Nurse



## CHILD/FAMILY



12 child/family dyads

Children aged 6 to 16

10 Mothers, 1 Grandmother & 1 Father

3 females

6 previous surgery

## RESULTS

### THEME

Variation of care

Outcomes

COVID-19

### CODE

- Different approaches used/received  
- Disagreement amongst clinicians

- Defining patient outcomes  
- Rationale for treatment approach

- Impact of COVID-19 on care

### WHAT WAS SAID

"that's what my consultant said. He was like, I'm so sorry, if you go and see any consultant, we'll all say something different" Mother of 6y

"When I first started work all the information was no impact" Physiotherapist

"you see a child with Perthes' and you genuinely don't really know in your heart of hearts the best treatment for them" Orthopaedic surgeon  
"I'm just...I don't know, I'm just waiting for it to go, if you know when it's going to go, you're waiting for your best day of your life basically" 10y male

"we've had COVID for two years so we, kind of, haven't been seen. We've just been shoved on a shelf" Mother of 9y

## CONCLUSION

Treatment for Perthes' Disease is varied

This study explains the variation in both the clinical setting and in the day to day lives of those affected by the condition



There is a need and a desire for robust evidence to support treatment choices

Agreement amongst clinicians is needed to optimise the care children with Perthes' Disease receive

