

# FAMILY PERSPECTIVES ON THE FEASIBILITY OF

## A CORTICOSTEROID INDUCTION REGIMEN TRIAL IN JUVENILE IDIOPATHIC ARTHRITIS

Sherratt, F.C. (sherratt@liv.ac.uk),<sup>1</sup> Roper, L.,<sup>1</sup> Baildam, E.,<sup>2</sup> Peak, M.,<sup>2</sup> McErlane, F.,<sup>3</sup> Stones, S.,<sup>4</sup> Young, B.<sup>1</sup>

<sup>1</sup>Department of Psychological Sciences, University of Liverpool; <sup>2</sup>Alder Hey Children's NHS Foundation Trust; <sup>3</sup>Great North Children's Hospital, Newcastle Hospitals NHS Foundation Trust; <sup>4</sup>University of Leeds

### 1. Introduction & Background



- Current delivery routes of corticosteroid treatment for juvenile idiopathic arthritis (JIA) are based on physician and patient preference, rather than scientific evidence.
- This qualitative study aims to inform the development of a future trial that will evaluate the most effective routes and doses of CS. In particular, we explored treatment preferences, acceptability of randomisation, willingness to participate, and deliberations regarding outcomes.

### 2. Methodology



- Semi-structured interviews with a purposive sample of patients and parents (N = 28) recruited via rheumatology clinics at four UK sites (9 children and 19 parents).
- Eligible families had children aged 1-16 years (although for children aged 7 years or less only the parents were interviewed), with recent experience (< 12 months) of CS treatment and either recent JIA diagnosis or flare.
- Interviews were audio recorded and transcribed. Data analysis drew on thematic analysis techniques.

### 3. Results



## VIEWS ON DELIVERY ROUTES



#### Intra-articular injection (IA)

- Most children had first-hand experience (n=13).
- Sporadic relief.
- More suitable for severe joint flares and cases with few affected joints.
- Immediate effect but trepidation about anaesthetic.

#### Methylprednisolone (tablets)

- Most children had first-hand experience (n=10).
- Often deemed ineffective.
- Less intensive and unsuitable for severe flares. Convenient but side effects were a concern.

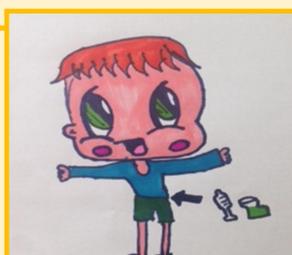


#### Intravenous Injection (IV)

- Half of children had first-hand experience.
- More intensive, fast-acting but sporadic in its relief.
- Those with experience reported facial puffiness and weight gain.
- Those without experience queried its suitability for young children.

#### Intra-muscular Injection (IM)

- Three children had first-hand experience (all >10 years old).
- Reported and perceived as fast-acting.
- One child said it was painful.
- No reported or perceived side effects.



## PARTICIPANTS' CONCERNS

- Participants tended to describe being more willing to participate at diagnosis than at flare-up. Parents reported diagnosis to be an intensely emotional time, at which they would prefer treatment certainty.
- Participants typically reported being less willing to participate at flare-up. Prior experience of delivery routes influenced perceptions of future treatment efficacy.

Five overarching themes emerged as key trial concerns:

#### Treatment suitability

"He had inflammation in about 36 joints... they said... 'give him some kind of aggressive treatment'. So that's what they addressed [IV] as - aggressive treatment" (Parent 9)

#### Treatment interactions

"I don't know, would they stop the Methotrexate or would they just carry it on?" (Parent 4)

#### Randomisation

"Computers wouldn't [know] what it's doing... whereas a person... they'd know themselves if they'd trained for years" (Child 12)

#### Travel/time

"I work full time... they're very restricted of what time you can have off" (Parent 6)

#### Quality of care

"I'd kind of probably take part in it... 'cause think if something didn't work on me I know that they'd just like, if I needed to they'd just put me on something else like in the end...?" (Child 9)



### 4. Conclusion



- No family appeared in equipoise regarding the delivery routes, largely due to previous treatment experiences.
- Recruitment of patients with flaring disease to a future trial will likely be challenging; treatment preferences were typically experience-based rather than anticipated.
- A key question clinicians will need to answer is: "If it's not worked this time, what makes them think it's going to work the second time?" (Parent 6).
- Confidence and reassurance from clinicians regarding treatment credibility and trial legitimacy could be key to participation willingness in a future trial.

#### About Juvenile Idiopathic Arthritis (JIA)

JIA is a heterogeneous collection of diseases affecting 15,000 children in the UK. Common symptoms include: joint pain, swelling and stiffness. Corticosteroids (CS) can help to achieve rapid disease control in children presenting with new or flaring JIA.

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