



An update for kids and parents from the CAPS study – Christmas 2017

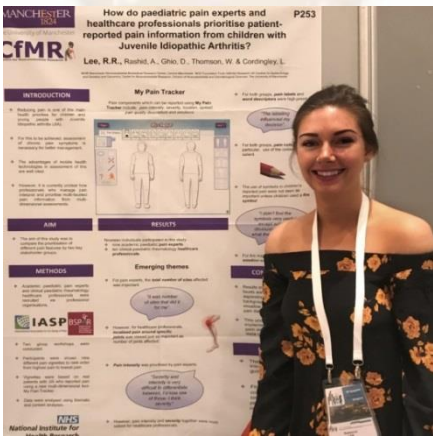
Welcome to the Christmas 2017 edition of the CAPS Newsletter! You have received this newsletter because either you or a member of your family is participating in the Childhood Arthritis Prospective Study (known as 'CAPS'). As ever, we would like to thank you for your continued support and provide you and your family with an update on how the study is progressing so far, and let you know about our current areas of research.

The Childhood Arthritis Prospective Study (CAPS) is funded by Arthritis Research UK and recruits children and young people newly diagnosed with arthritis.

CAPS is based at the University of Manchester, began recruiting in 2001 and has recruited over 1600 patients to date.

The aim of the study is to find those things that may help predict how patients will manage over the long-term. Better understanding of the course of the illness will help in choosing the best treatment for children now and in the future.

News and updates from the CAPS Study



Recently, our researchers have been to the annual meetings of the Paediatric Rheumatology European Society (PREs) in Athens and the American College of Rheumatology (ACR) in San Diego to discuss their latest work with data from CAPS.

One of our PhD students, Rebecca Lee, presented work at PREs on use of children's pain data in making decisions about how bad pain experiences are, both in research and in clinic.

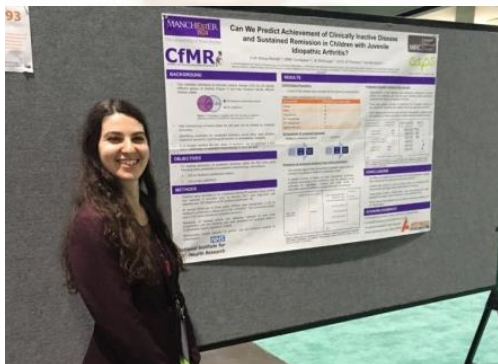
For this study, researchers and healthcare professionals, who are usually the people who look at pain data in research and clinic, met in groups to discuss different children's pain data and how severe different pain reports looked to them. Rebecca found that researchers and healthcare professionals focused mainly on intensity of pain, e.g. how bad children said the pain was from 1 to 10.

Rebecca also found that both researchers and healthcare professionals were interested in where the pain was and how many places the pain affected. This research is important because it tells us more about how decisions are made on how to manage pain in patients in research and clinic.

CAPS recruits patients from 7 centres across the UK:

- Alder Hey Children's Hospital (Liverpool)
- Royal Hospital for Sick Children (Edinburgh)
- Great Ormond Street Hospital (London)
- Royal Manchester Children's Hospital
- University College London Hospital
- Royal Hospital for Children (Glasgow)
- Great North Children's Hospital (Newcastle)

73 participants have been recruited to the study in 2017. Dr Alice Chieng and the team at Royal Manchester Children's Hospital have recruited the most so far!



This shows that although there are some differences in how researchers and clinicians interpret pain, the conclusions they come to are very similar in the end. We now need to do more research on the different interpretations of children's pain data between these two groups.

Stephanie Shoop-Worrall, who is also studying for a PhD using CAPS data, presented two different studies at PREs and ACR. The first was a study to look at what happens over the first five years after a child or young person is diagnosed with Juvenile Idiopathic Arthritis (JIA). On average, both signs of disease and symptoms like pain and wellbeing improve the most over the first year after being diagnosed with JIA.

After this time, on average, both signs and symptoms of JIA stay the same for the next four years. Children who have fewer than five swollen joints when they are diagnosed with JIA have a better outlook than those who have five or more swollen joints (*continued over*).





CAPS research (cont.)

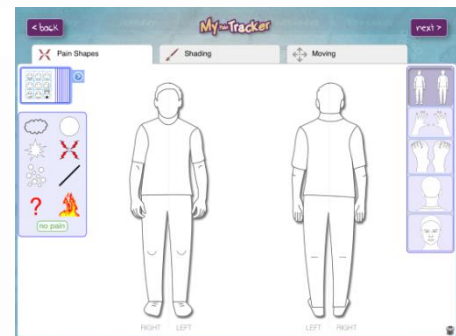
Stephanie’s second study was to help us understand which children and young people with JIA will go into remission after one year and why. After one year in the CAPS study, around one third of participants were in remission. We found that being older when you are diagnosed with JIA and being more able to do daily activities gave a higher chance of remission. Children who have fewer than five swollen joints when they are diagnosed with JIA were more likely to go into remission than those who had five or more swollen joints.

There are different types of JIA with related symptoms and similar treatments. However, it is sometimes difficult to know which type a patient belongs to and it is possible that using genetic information could help. Dr Anne Hinks ran a study which has found differences in the genetic information, on a region on chromosome 6, which may help us to decide how to define the different types of JIA. This study also showed that one of these types of JIA is genetically similar to adult rheumatoid arthritis (RA). This may help us to have a greater understanding of the causes of JIA and ultimately new treatments. At the ACR, this research paper was mentioned in the ‘Year in Review’ part of the meeting as ‘the most important paper this year in paediatric rheumatology’.

CAPS researcher Roberto Carrasco has studied the height of children with JIA to see what might cause poor growth in these children. Roberto looked at data from 568 patients over a 3 year period. He found that patients were average height for their age and gender when they were diagnosed. However, after 3 years, some patients were shorter than they should have been for their age and gender, with 39% having restricted growth. Despite this, patients with the lowest initial height scores were also the most likely to see an improvement after 3 years. The impact of JIA on growth is important to children and families and this study provides useful new data to support clinical care.

‘My Pain Tracker’ update

My Pain Tracker (MPT) is a new app that the research team at CAPS have developed for children and young people with pain and JIA. The app ‘tracks’ pain through the use of symbols, faces, words and colours. The app also asks questions about what the pain has stopped you from doing during the day. Recently, we have been using the app to help us collect data for different studies.



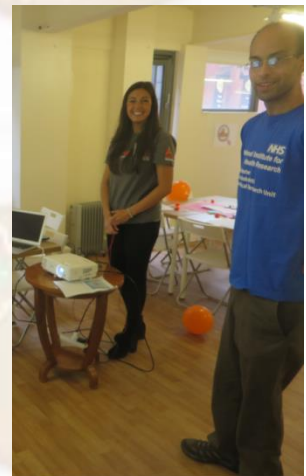
We wanted to see whether children and young people liked using the app at home to track their pain. After using the app for one week, we found that children liked that they could track how pain made them feel and how their pain had been over time. Using the app also made it easier for them to talk to their parents and doctors about their pain.



Currently, we are investigating how often children and young people would like to use the app at home, as we do not want to burden children with tracking their pain, but we also do not want to miss important information.

The research team conducting the My Pain Tracker (MPT) study hosted a recruitment event at Ziferblat in Manchester during the summer holidays. During the afternoon, we did a presentation about the research we are working on, what we recently found and what we are hoping to do next. We also drew around our researcher Diederik to make a life-size pain mannequin (see picture).

We are hoping to host some more events like this next year so we might be in touch with you soon to invite you along!



Contact us!

We would love to hear from you if you have any questions or if there is anything you would like to see in future newsletters. Contact us as below:

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