

Using My Pain Tracker to improve assessment and communication about pain in Juvenile Idiopathic Arthritis



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Brief re-cap of My Pain Tracker

- An iPad app developed for children and young people (**aged 5- 16**) with **Juvenile Idiopathic Arthritis (JIA)**
- Captures **multi-dimensional** pain reports over time, remotely from children and young people who record data at home;

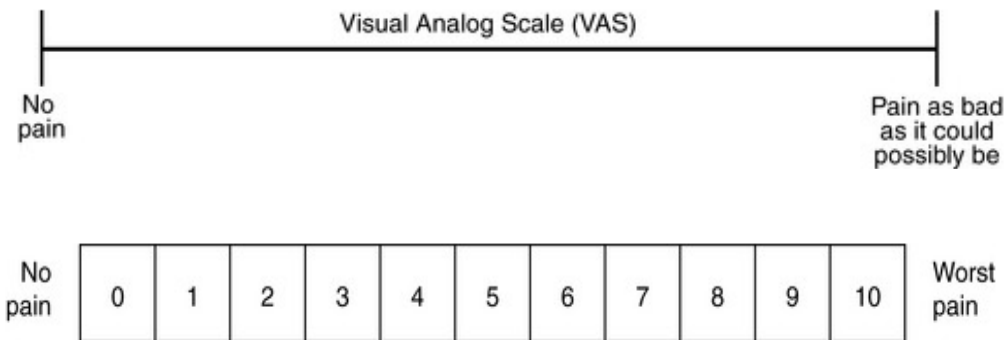
Pain Location
Pain Size
Pain Throb/Movement
Pain Emotion
Pain Qualities
Pain Interference



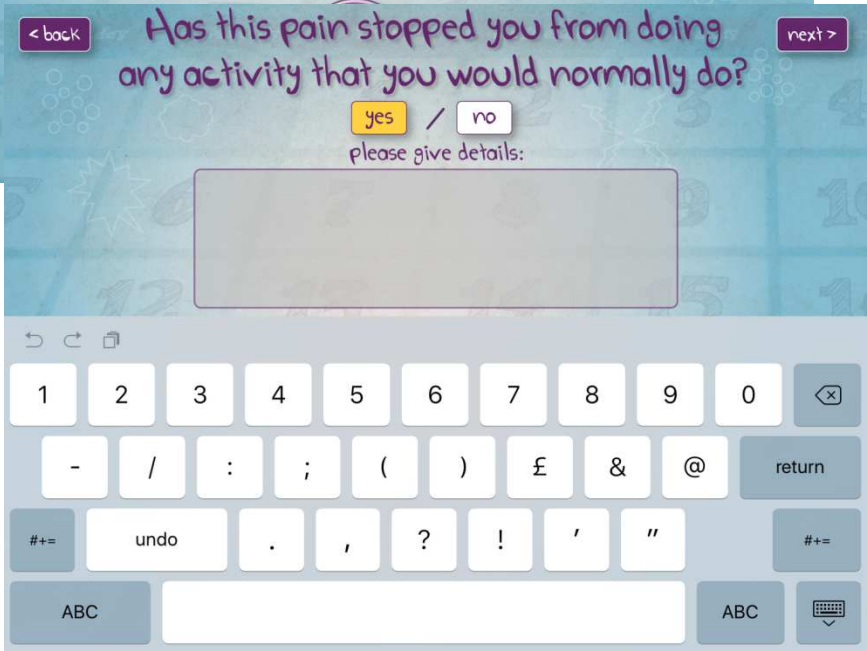
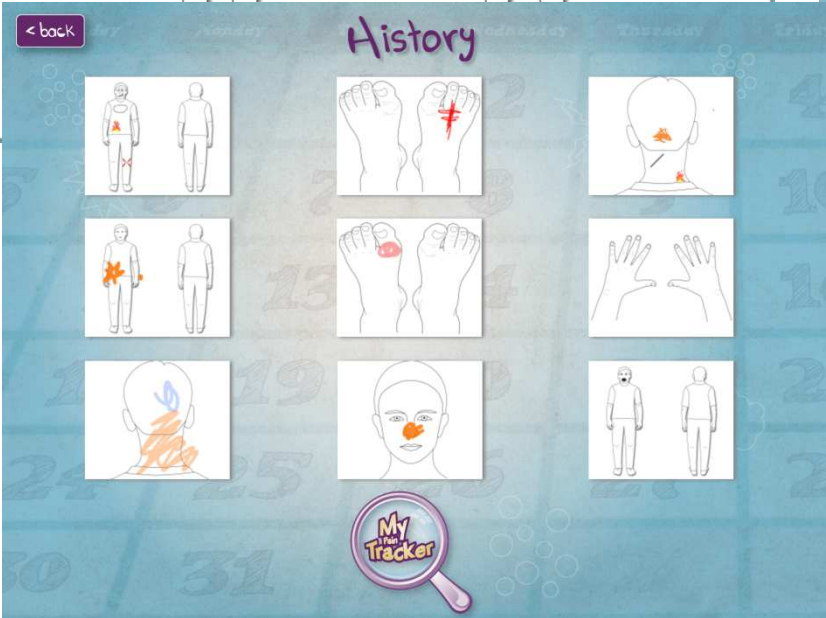
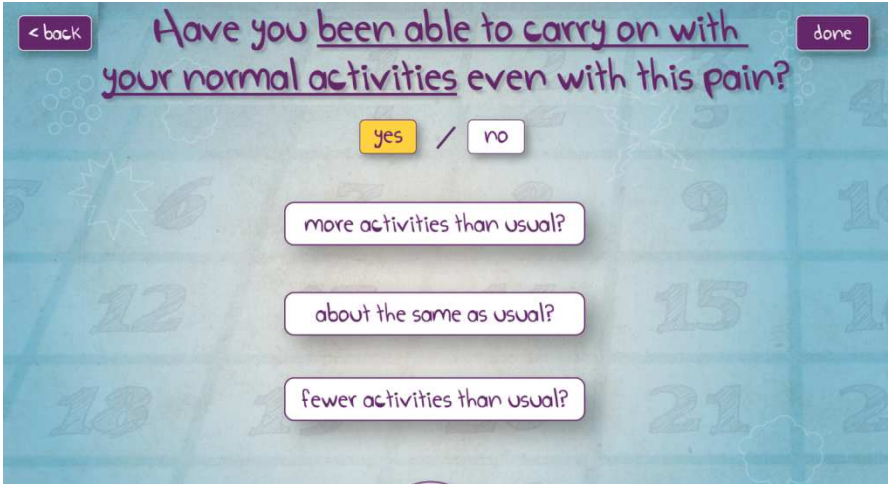
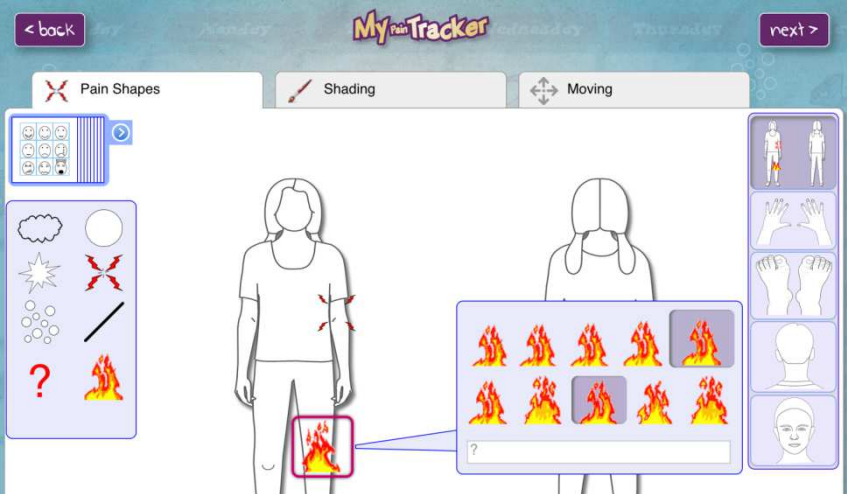
Have a go...Pain Assessment

Think about the last time you had pain.

How would you use these scales to help you communicate how this felt to somebody else?



Have a go...My Pain Tracker



Communication about pain

The nature of using MPT in a chronic pain context is very different to the original IMS context

In My Shoes



Used to help a **professional skilled in eliciting information** about pain, from a **child who might not want to talk** about issues openly...

My Pain Tracker



Used to help **children prompt and facilitate** a conversation about pain, with a **professional who does not know what to do** with that information...

Communication about pain



Use MPT as a 'mental repository' which unburdens them to some extent from pain experiences

Children with JIA

Use MPT structure and features to help them understand and communicate pain

Find capturing pain patterns regularly and in detail useful for planning activities and/or managing pain

Communication about pain

Have a lack of training/confidence in discussing pain



Largely undervalue pain because it does not always respond to medicine

Do not fully understand the nature of pain in the disease

Professionals managing JIA

Are reluctant to approach the topic of pain because they do not know how to manage it

Believe that focusing on pain leads to over-exaggeration of pain symptoms

Managing the divide between children with JIA and professionals

Children with JIA

- We needed to understand more about how children and young people want to use MPT at home



- We needed to know that we were not making pain 'worse' through asking too frequently about it



Professionals managing JIA

- We needed to make it easier for professionals to use the information collected by MPT by condensing data to a manageable level



Our studies using MPT with children

Questions we have aimed to answer in our work with children;

1. What is the best way for children and young people with arthritis to use these tools?
2. How often do children want to report?
3. Can they sustain that over time?
4. Does more/less intense pain reporting affect their pain experiences (a phenomenon called measurement reactivity)?



MPT with children



Recruitment event for
study

MPT with children

- ‘N-of-1’ trial with 14 children with JIA
- Explored four different time-sampling strategies; *once-a-day*, *twice-a-day*, *once-a-week* and *as-and-when*
- Assessed *pain interference each week* (to observe artefacts of measurement reactivity)
- Explored *advantages/disadvantages* of each strategy



MPT with children

Adherence:

- Once-a-week reporting was highest (**62.5%**)
- followed by once-a-day (**50.6%**)
- then twice-a-day (**37.8%**)

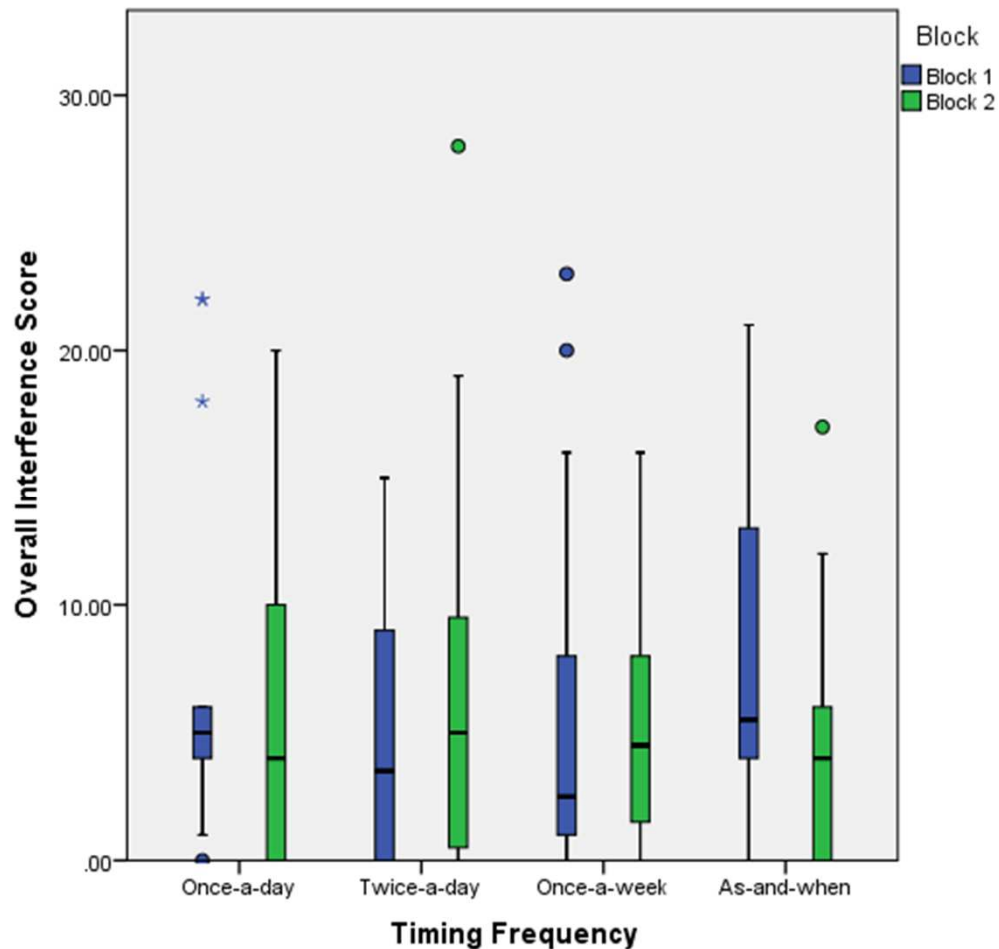
As-and-when reporting ranged from **0 to 7** reports during the two weeks this schedule occurred for participants

Conclusions:

Even the most adhered to schedule only achieved 62.5% adherence. Was the protocol for our study too burdensome or are these findings due to a longer data collection period than usual for these types of studies?

MPT with children

First completion of schedule VS second completion of same schedule



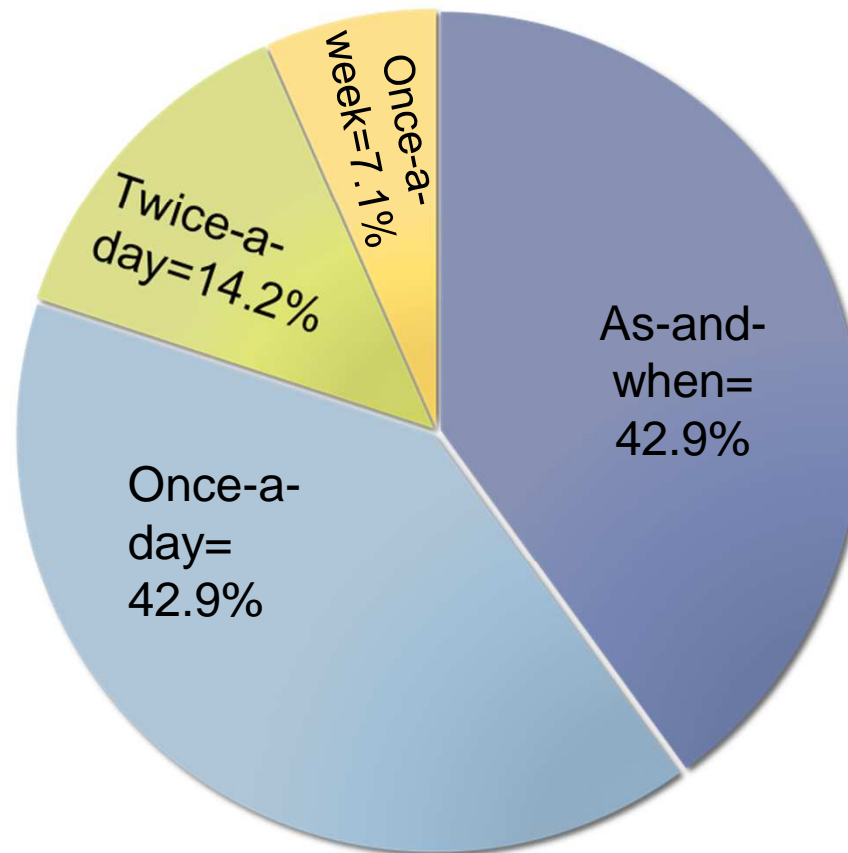
No significant differences in pain interference scores between timing frequencies, compared with the once-a-day schedule;

- once-a-week $p=0.984$
- twice-a-day $p=0.588$
- as-and-when $p=0.563$

No evidence of objective measurement reactivity in terms of pain interference

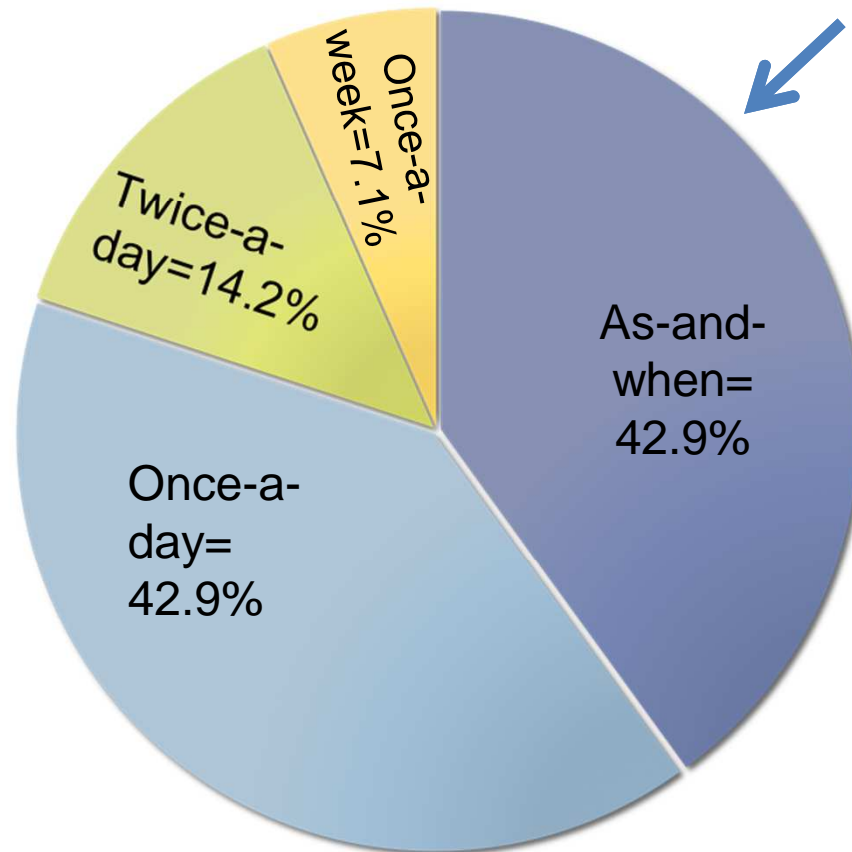
MPT with children

- Easy to remember to complete-embedded in routine
- Accommodates reporting of 'good' pain days
- Captures comprehensive patterns that children can look back on



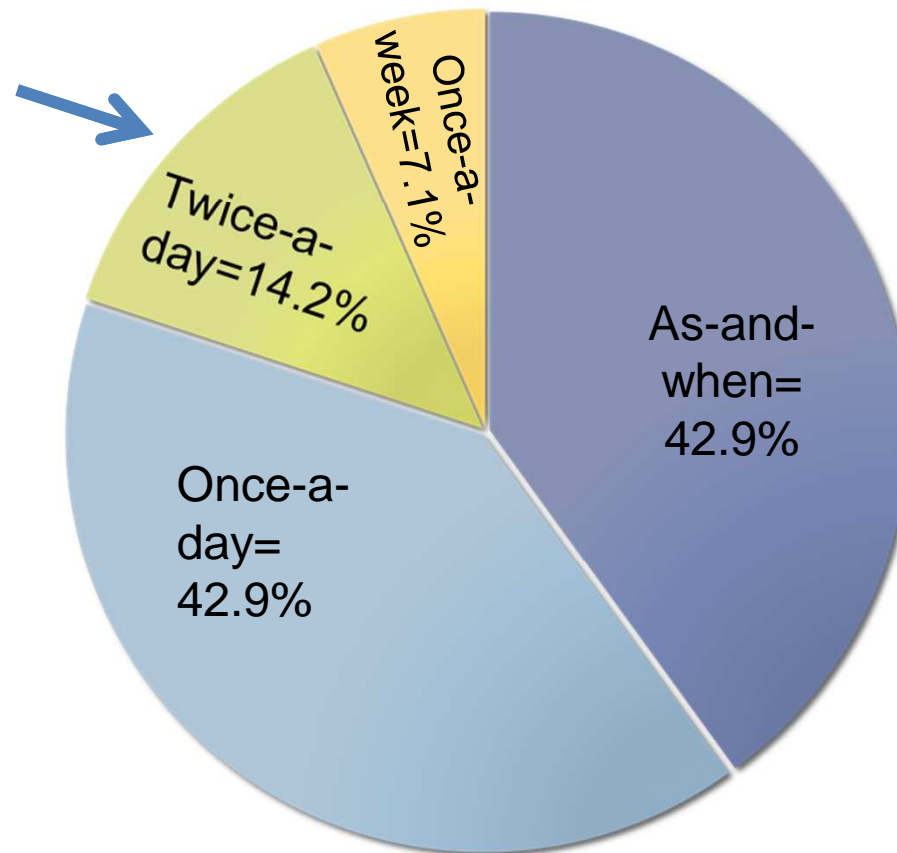
MPT with children

- Flexibility of this burdensome for some participants (have they had enough pain to report?)
- Misses 'good' pain days



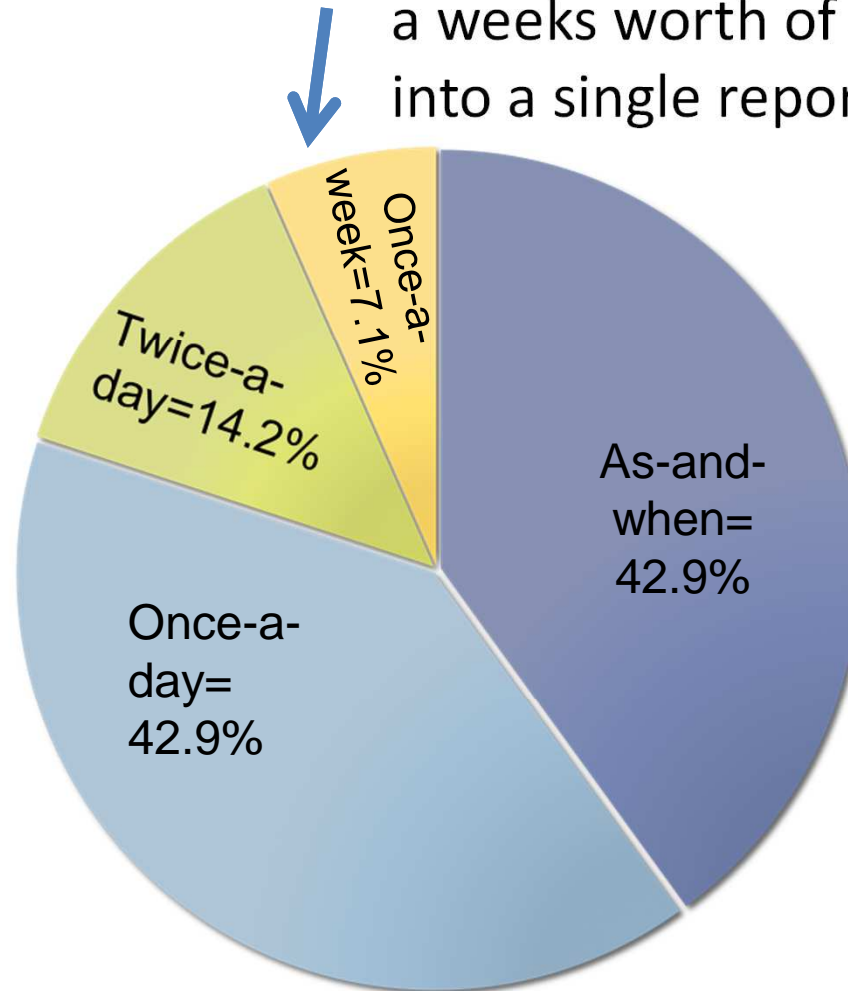
MPT with children

- Captures within day variations in pain
- Can be emotionally challenging to be persistently reminded about pain
- Too difficult to space apart and fit into everyday



MPT with children

- Not regular enough to remember to report pain
- Difficult to incorporate a weeks worth of pain into a single report



MPT with children and conclusions

- **Daily reporting of pain** is most feasible and preferred from children and young peoples perspectives with JIA
- **No evidence of objective measurement reactivity** or impact upon interference, although some children and parents perceived small changes in mood and fatigue in more intense reporting schedules (reported in interviews)
- Findings are encouraging for clinical professionals to **ask about pain more frequently**

Our studies using MPT with professionals

Questions we have aimed to answer in our work with professionals;



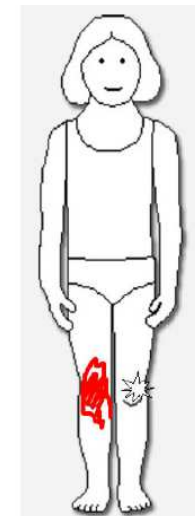
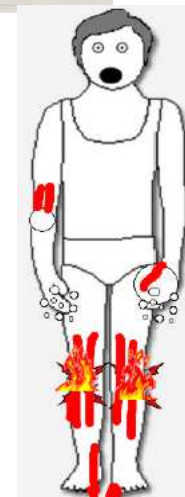
1. What types of reported multi-dimensional pain information do professionals pay most attention to when prompted to interpret childrens reports?
2. How can we use this information to build a pain data 'visualisation' which is easy to understand and which could be used by professionals managing children with JIA in clinic?

MPT with professionals

- **Two focus groups**; one with pain specialists and one with rheumatology specialists

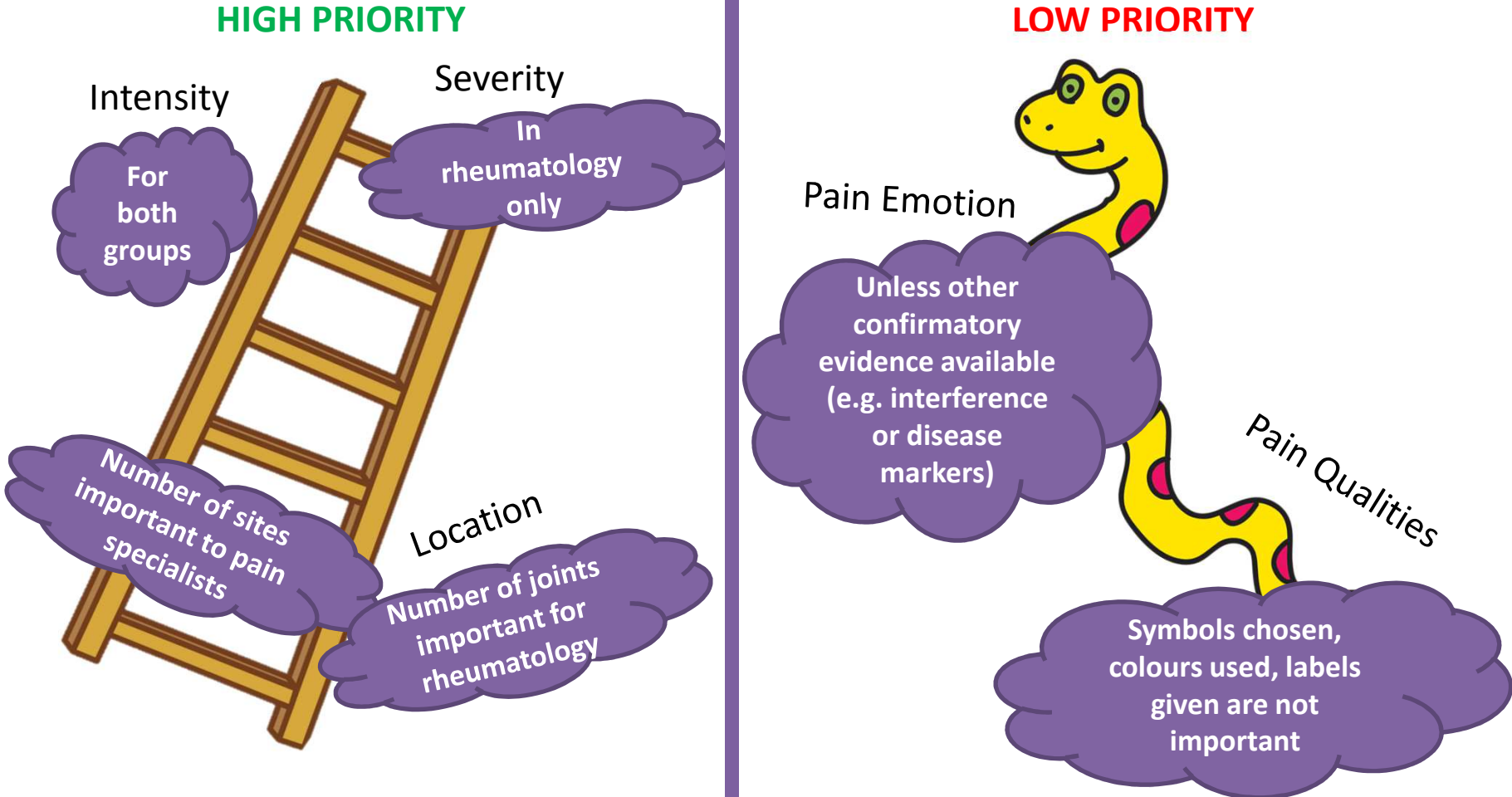


- Groups given **vignette scenarios** of real MPT data to rank order (to prompt discussion on the reasoning behind interpretations)



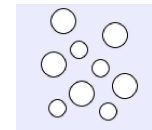
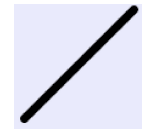
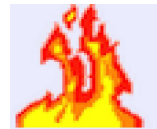
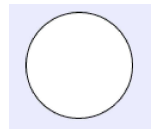
MPT with professionals

Pain interpretation



MPT with professionals and conclusions

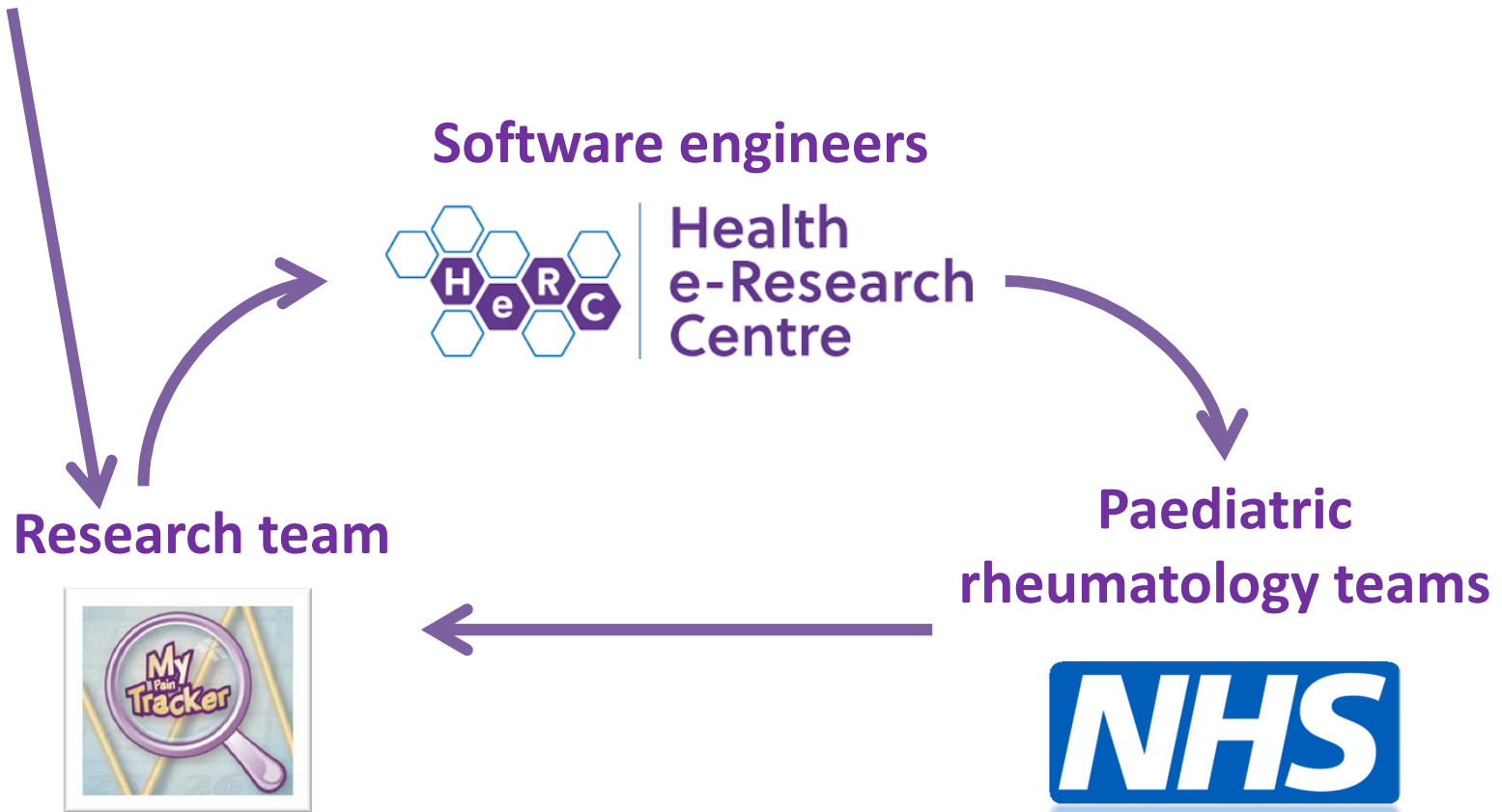
- **Different interpretations** of the **same pain data** by pain and rheumatology specialists
- Importantly, not all pain components children want to be able to report are used to inform interpretations so we need to be **selective on what we present** to professionals



- Findings indicated that **some aspects of data** (e.g. emotion and interference) **need to be presented simultaneously** to make sense so how we present data is also important...

MPT with professionals

Findings were used to inform the design of initial pain data visualisations which corresponded to the data collected by MPT



MPT with professionals



PATIENT
John Smith

Overview



From

Sun 1 April 2018

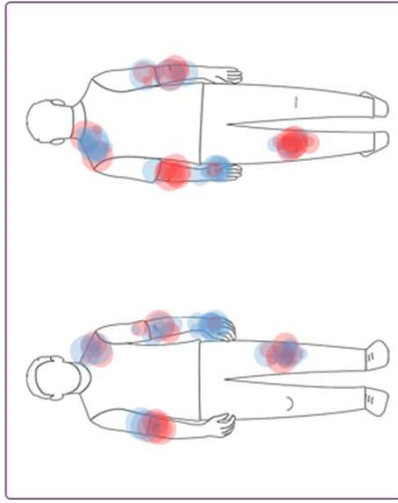


To

Sat 30 June 2018



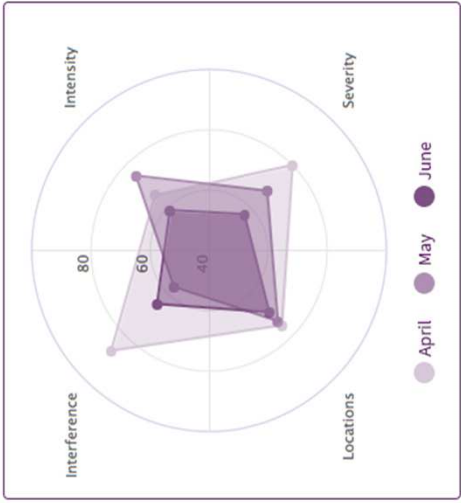
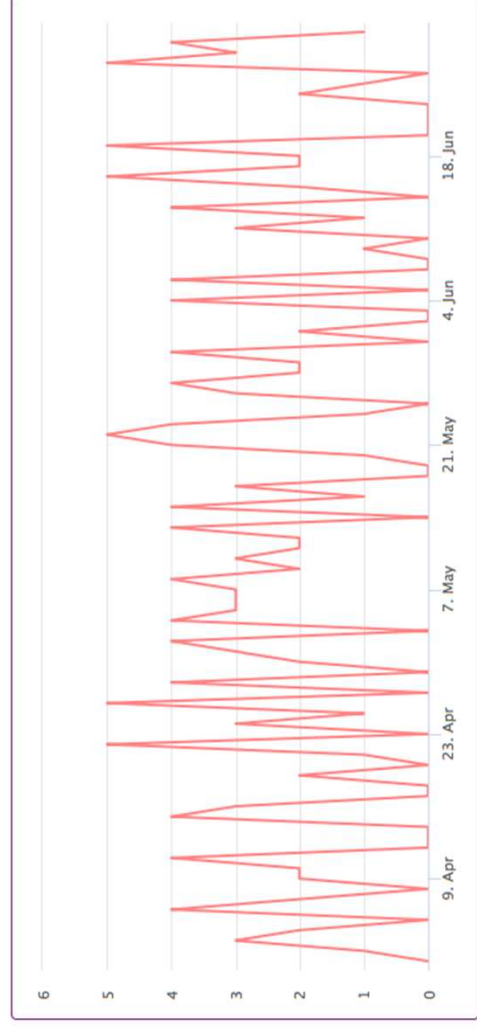
OVERVIEW | BODY FRONT/BACK



LOCATIONS



SEVERITY



PATIENT **John Smith**

INTERFERENCE

Interference From To

June 2018



- Morning
- Afternoon
- Evening
- No pain
- No data
- Interference
- No Interference

Other current challenges in MPT context

- Rebuilding app and software to work across multiple platforms (e.g. IOS and Android) and with a capacity to have many more users



- Exploring what type of things we can work out from the data collected in larger samples e.g. can we use the app as a outcome measure in clinical trials and/or score the app in a way which helps us to identify pain phenotypes?
- Exploring whether we can we use the app in other pain conditions (e.g. chronic idiopathic pain or fibromyalgia)

Any questions?



Thank you!

Children and parents



Childhood Arthritis Prospective Study

Healthcare professionals



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