

How can digital technology be used to improve communication about pain?



Dr Rebecca Lee

What is pain?



- Pain is *subjective*
“Pain is whatever the experiencing person says it is, existing whenever they say it does” (McCaffery, 1968).
- Pain has *biological*, *psychological* and *social* components and is *multi-dimensional*
- Pain exists even in those who are not able to *verbalise* it (e.g. newborns and infants)

Defining pain is difficult and definitions are still debated

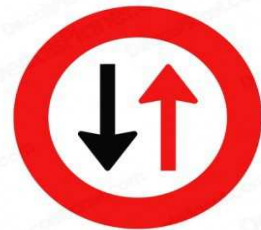
(IASP, 1994; Williams & Craig, 2016; Cohen et al, 2018)

Language and development stage restricts our ability to describe exactly what we mean when we talk about pain

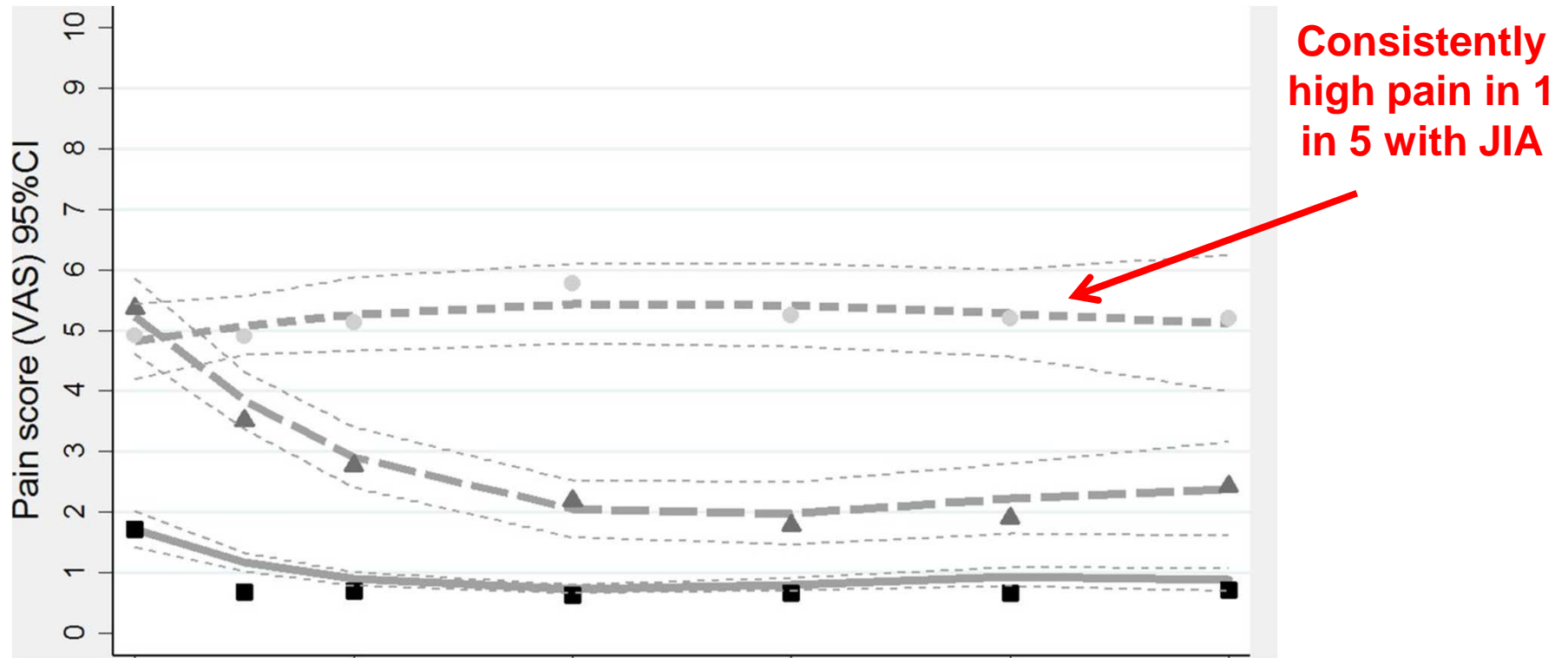
This has important implications in terms of the methods we use to assess, measure and communicate about pain

Pain in arthritis

- **Juvenile Idiopathic Arthritis (JIA)** affects approximately every 1 in 1000 children (Thierry et al, 2014)
- Pain is **chronic** (Schanberg et al, 1997)
- Pain is **unpredictable** and can fluctuate in intensity, duration, location and quality (Benestad et al. 1996; Schanberg et al, 2003)
- The **invisible nature of pain** in JIA has been described as “the worst thing” about living with the condition (Tong et al, 2012)
- Pain levels **do not always mirror** inflammation and disease (Thastum & Herlin, 2013; Lomholt et al, 2013)



Pain in arthritis



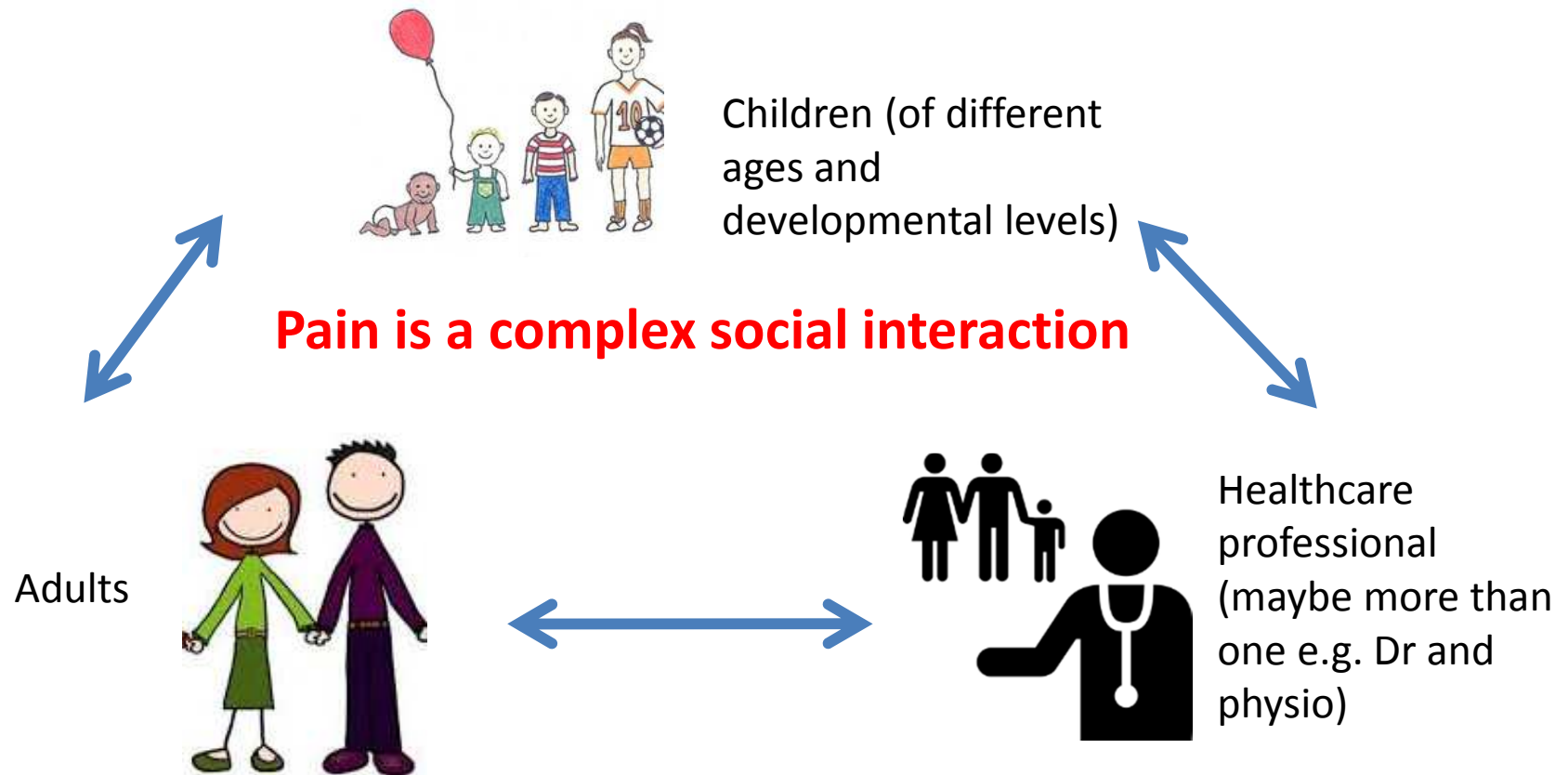
Findings from Rashid et al, 2017: Data from 851 individuals with JIA, followed over 5 years (Baseline, 6 months, 1, 2, 3, 4 and 5 year follow-up)

Importance of assessing and communicating about pain

- For *diagnosis, management* and *treatment* of pain (Lund et al, 2005).
- Associated with *improvements* in pain (Hirschfeld, 2014).
- Can prompt a conversation about pain which can *validate* patients experiences (Defenderfer et al, 2018).



Who needs to communicate about pain?



Who needs to communicate about pain?

Children have to understand, process and express pain information which is particularly difficult for younger people (Chan & von Baeyer, 2016).



Children (of different ages and developmental levels)

Adults



Healthcare professional (maybe more than one e.g. Dr and physio)

Who needs to communicate about pain?

Parents are poor at predicting and understanding their child's pain

(Chambers et al, 1998;1999).



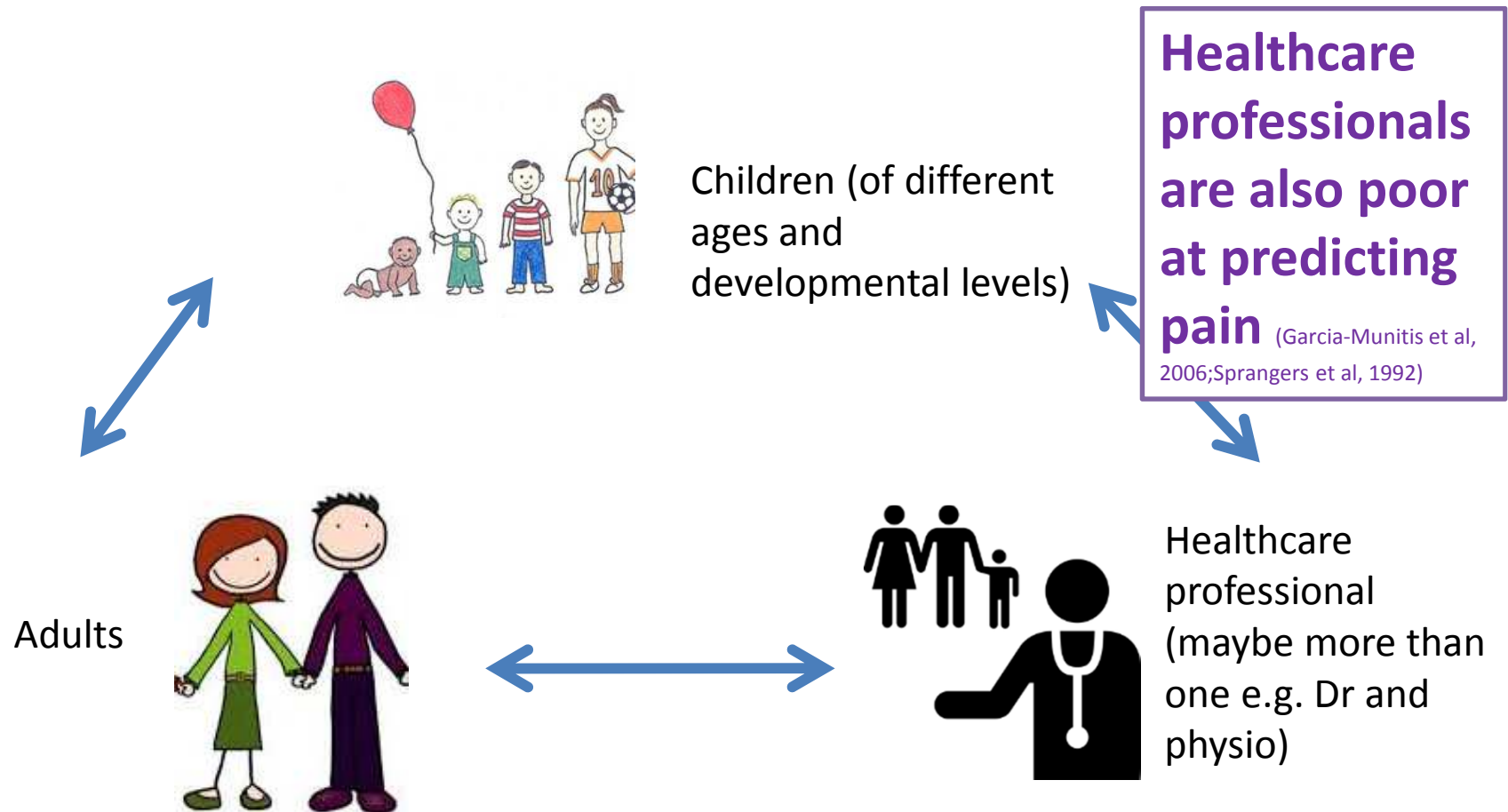
Children (of different ages and developmental levels)

Adults



Healthcare professional (maybe more than one e.g. Dr and physio)

Who needs to communicate about pain?



What do children need to communicate about pain?

How long have they had pain?

How severe is the pain?

What does pain stop them from doing?

How does pain make them feel?

How intense is the pain?

What can they still do with pain?

How long does it last?

Where do they get pain?

What triggers the pain?

What time of day is pain best/worst??

How would they describe its qualities?

What do children need to communicate about pain?

How long have they had pain?

How severe is the pain?

What

How intense is the

+ Other symptoms which need to be reported, which are often **higher priority to professionals**

How long does it last?

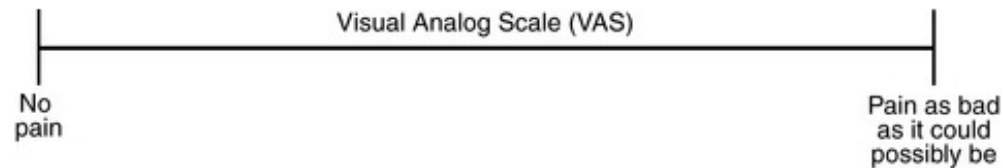
What triggers pain?

How is pain best/worst??

How would they describe its qualities?

Where do they get pain?

Tools for assessing pain in children



These scales might look simple, but are cognitively demanding to complete.

How do you summarise;

- Pain in more than one location?
- Pain over long periods of time?
- Pain which changes throughout the week/day?
- How pain has made you feel?
- How pain has impacted on other things?
- How you are coping with pain?

These scales leave a lot left to talk about!



| | | | | | | | | | | | | |
|---------|---|---|---|---|---|---|---|---|---|---|----|------------|
| No pain | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst pain |
|---------|---|---|---|---|---|---|---|---|---|---|----|------------|

A new tool for children with arthritis needed, which could:

1. Capture nuances and patterns in pain over time (e.g. chronicity and unpredictability of certain features)

2. Capture the multi-dimensionality of pain and help children understanding and process pain specific experiences

3. Aid communication across a developmental spectrum and help to create a sense of 'validation' of pain experiences with parents and professionals

4. Be engaging, useful, user-friendly, practical to complete and most importantly- **FUN!**



My Pain Tracker

My Pain Tracker (MPT) is an *iPad app* which captures:

- Pain Location
- Pain Size (Severity)
- Pain Throb/Movement (Intensity)
- Pain Emotion
- Pain Qualities (Depicted Through Symbols, Colour Shading And Pain Labels)
- Pain Interference



Where did My Pain Tracker come from?

- Rachel Calam (2000, Clinical Psychologist, University of Manchester) and team developed 'In My Shoes'
- A computer assisted interview tool for paediatric mental health contexts (upsetting, painful experiences such as abuse)
- Modules on emotions, different contexts and settings (e.g. home, school or particular people) and a somatic experience module about pain qualities

Assessment and Therapy with Children:
Can Computers Help?

RACHEL CALAM
University of Manchester

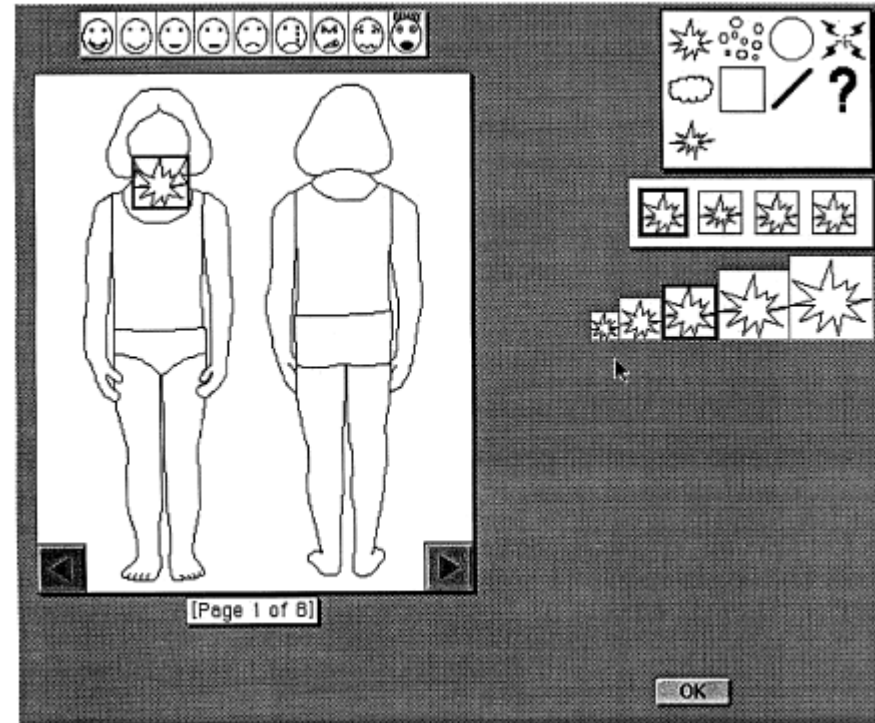
ANTONY COX
Guy's Hospital

DAVID GLASGOW
Calderstones Hospital

PHIL JIMMIESON
University of Liverpool

SHEILA GROTH LARSEN
Liverpool

Where did My Pain Tracker come from?



Dr Lis Cordingley (Health psychologist)

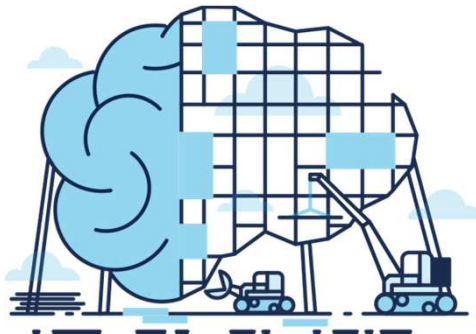
Professor Wendy Thomson (Professor of Genetic epidemiology)

believed the tool could have utility for those with acute and chronic pain conditions outside the mental health context...

Why use In My Shoes as a basis for My Pain Tracker?

In My Shoes provided *key advantages*:

1. Multi-dimensional somatic pain module
2. Electronic data collection
3. Quantifiable outcomes
4. Components designed for and with children and young people so developmentally appropriate
5. Provides a 'scaffold' or 'structure' for cognitions (understanding and processing pain)



Development from IMS to MPT

- Interview assisted
- Used in mental health context
- Many modules, of which pain is one



2000

In My Shoes



In My Shoes

2019

My Pain Tracker



Development from IMS to MPT

- Pain and emotion modules used with post-operative children
- 30 children aged 7-12
- Completed tool immediately after surgery and at 2 time-points (30 min apart) the next day
- Convergent validity (compared to VAS and FPS-R) and test-retest validity established in acute pain



2000

In My Shoes



In My Shoes

**Watson *et al*
2002**

2019

My Pain Tracker



Development from IMS to MPT

- Used with 32 children and young people (8- 17 years) with recurrent pain (widespread pain sample from gastro and rheumatology)
- Convergent validity with VAS and FPS-R established
- Face validity: children liked its novelty, its comprehensiveness, its ease and that it was personalised



2000

In My Shoes



In My Shoes

**Twynholm *et al*
2002**

2019

My Pain Tracker



Development from IMS to MPT

- iPad specific adaptation
- First use of the tool within a specific complex disease context
- Acceptability, usability and validity established with 47 children with JIA
- Start to adapt pain and emotion modules for this group: back/front manikin view, fire icon added, zoom palette for smaller joints



2000

In My Shoes



2013

This feeling!



2019

My Pain Tracker



Development from IMS to MPT

- Development into standalone, pain assessment tool for use at home...



2000

In My Shoes



2013

This feeling!



2019

My Pain Tracker



What else is new in My Pain Tracker?

Moving away from an interview lead tool, other new features were necessary:

- No pain option-Important to accommodate relapsing-remitting nature of pain and not over-burden children with completion
- Pain interference- Important to capture the context of pain experiences
- Database and back end infrastructure- Important to review how data is saved, scored and presented to stakeholders (researchers, clinicians, academics, students, parent and patients)



< back

My Pain Tracker

next >



Pain Shapes

Grid of pain shape icons: a 3x3 grid of smiley faces, a cloud, a starburst, a circle, a lightning bolt, a line, a flame, a question mark, and a group of circles.

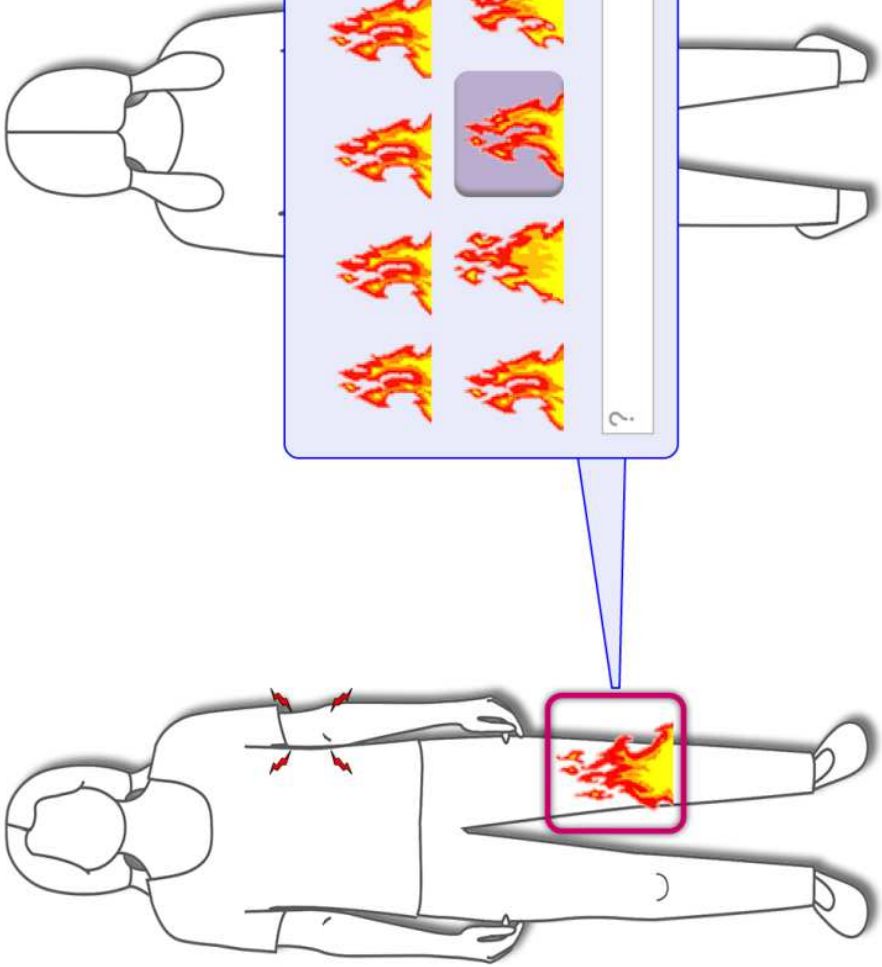


Shading



Moving

Body part selection icons: a full-body figure, a hand, a foot, a head, and a face.



Callout box containing a 2x5 grid of flame icons, a question mark, and a text input field.



< back

Has this pain stopped you from doing
any activity that you would normally do?

next >

yes

/

no

please give details:



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ABC



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Have you been able to carry on with your normal activities even with this pain?

done

yes

/

no

more activities than usual?

about the same as usual?

fewer activities than usual?



How are we using My Pain Tracker with children?

What is the best way for children and young people to use these tools?



How often do children want to report? Can they sustain that over time? Does this affect their pain experiences?

More information at the workshop...

How are we using My Pain Tracker with parents?

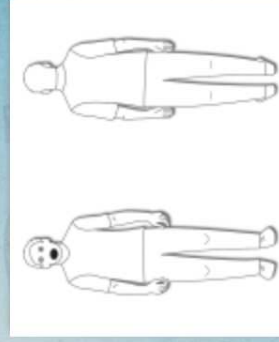
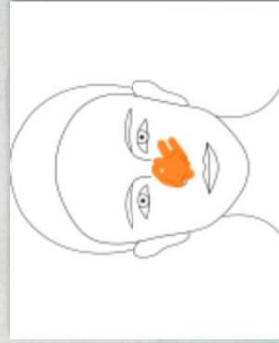
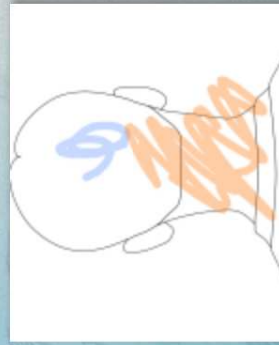
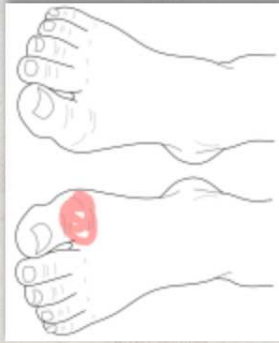
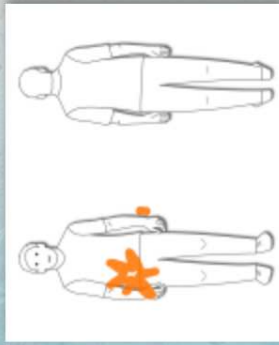
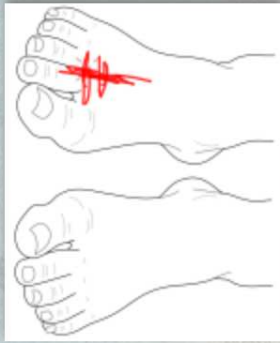
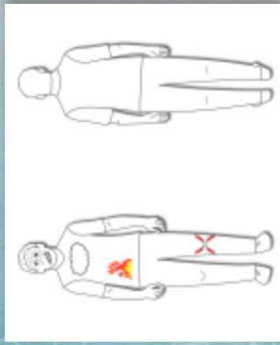
- Using pain histories to prompt conversations about pain patterns at home
- Using pain histories to help parents structure conversations to healthcare professionals (information which children sometimes decide not to share in clinic)

“Sometimes he won’t tell us when he’s hurting...it’s a good way to find out if he has been sorer than what he’s been saying. ..He’s felt like he can talk to that”,



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History



How are we using My Pain Tracker with healthcare professionals?

In other research, we explored and identified many reasons for why professionals do not communicate about pain with children with JIA



Original Article | Open Access |

'Reluctant to assess pain': A qualitative study of healthcare professionals' beliefs about the role of pain in Juvenile Idiopathic Arthritis

Rebecca Rachael Lee, Amir Rashid, Wendy Thomson, Lis Cordingley

One problem we can address with MPT: “A lack of time to gather pain information, as well as a lack of tools which help make these conversations more efficient”

More information at the workshop...

My Pain Tracker workshop-This afternoon

- Demonstrations of My Pain Tracker app
- More information on our studies with children and young people with JIA and My Pain Tracker
- More information about our work with healthcare professionals and clinical use of My Pain Tracker
- Other current challenges we face in MPT development work

Thank you!

Children and parents



Childhood Arthritis Prospective Study

Healthcare professionals



Research team

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Daniela Ghio
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