CHILDREN & YOUNG PEOPLE
AUTISM PAIN AUDIT

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Where it all began

- 2013
- Pain assessment tools

**PAEDIATRIC PAIN ASSESSMENT**

**FLACC Scale**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face</td>
<td>No particular expression or smile</td>
</tr>
<tr>
<td></td>
<td>Occasional grimace or frown, withdrawn, disinterested</td>
</tr>
<tr>
<td></td>
<td>Frequent to constant frown, clenched jaw, quivering chin</td>
</tr>
<tr>
<td>Legs</td>
<td>Normal position or relaxed</td>
</tr>
<tr>
<td></td>
<td>Uneasy, restless, tense</td>
</tr>
<tr>
<td></td>
<td>Kicking or legs drawn up</td>
</tr>
<tr>
<td>Activity</td>
<td>Lying quietly normal position moves easily</td>
</tr>
<tr>
<td></td>
<td>Squirming, shifting back and forth, tense</td>
</tr>
<tr>
<td></td>
<td>Arched, rigid or jerking</td>
</tr>
<tr>
<td>Cry</td>
<td>No cry (awake or asleep)</td>
</tr>
<tr>
<td></td>
<td>Moans or whimpers, occasional complaint</td>
</tr>
<tr>
<td></td>
<td>Crying steadily, screams or sobs, frequent complaints</td>
</tr>
<tr>
<td>Consolability</td>
<td>Content, relaxed</td>
</tr>
<tr>
<td></td>
<td>Reassured by occasional touching, hugging or ‘talking to’, distractable</td>
</tr>
<tr>
<td></td>
<td>Difficult to console or comfort</td>
</tr>
</tbody>
</table>

Each of the five categories Face (F), Legs (L), Activity (A), Cry (C), Consolability (C), is scored from 0—2. This results in a total score of 0—10.
Where it all began

- Revision and update
- Implementation

### PAEDIATRIC PAIN ASSESSMENT

**SCORING SYSTEM FOR INFANTS, YOUNG CHILDREN, COGNITIVELY IMPAIRED CHILDREN, ANXIOUS CHILDREN AND ANY CHILD UNABLE TO USE FACES LADDER**

**FLACC Scale**

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Face</strong></td>
<td>No particular expression or smile</td>
<td>Occasional grimace or frown, withdrawn, disinterested, sad, appears worried.</td>
<td>Frequent to constant quivering chin, clenched jaw, distressed looking face, expression of fright/panic.</td>
</tr>
<tr>
<td><strong>Legs</strong></td>
<td>Normal position or relaxed; usual tone and motion to limbs.</td>
<td>Uneasy, restless, tense, occasional tremor.</td>
<td>Kicking, or legs drawn up, marked increase in spasticity, constant tremors, jerking.</td>
</tr>
<tr>
<td><strong>Activity</strong></td>
<td>Lying quietly, normal position, moves easily, regular, rhythmic respirations.</td>
<td>Squirming, shifting back and forth, tense, tense-guarded movements, mildly agitated, shallow/splitting respirations, intermittent sighs.</td>
<td>Arched, rigid or jerking, severe agitation, head banging, shivering, breath holding, gasping, severe splinting.</td>
</tr>
<tr>
<td><strong>Cry</strong></td>
<td>No cry (awake or asleep)</td>
<td>Moans or whimpering: occasional complaint, occasional verbal outbursts, constant grunting.</td>
<td>Crying steadily, screams or sob, frequent complaints, repeated outbursts, constant grunting.</td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>Content, relaxed</td>
<td>Reassured by occasional touching, hugging, or being talked to: distractible</td>
<td>Difficult to console or comfort, pushing caregiver away, resisting care or comfort measures.</td>
</tr>
</tbody>
</table>

Each of the five categories Face (F), Legs (L), Activity (A), Cry (C), Consolability (C), is scored from 0—2. This results in a total score of 0—10.
Pain Assessment

- Pain assessment is commonly achieved using self-report or observational tools. Whilst self-report tools are typically used with developing children, impaired communication skills make self-report questionable for children with ASD. (Breau & Burkitt, 2009; Craig, 2009)

- Observational pain assessment may be difficult to undertake due to idiosyncratic behaviours associated with ASD. This may result in misestimates of pain by those who are not familiar with the child's typical behavioural responses. (Fanurik et al, 1999; Bottos & Chambers, 2006)
Why we Decided to Audit

- Pain assessment tool not suitable for all.
- Poor evidence of previous pain history.
- Question sent to all PPTC group members.
- Poor response: 67 centres contacted
  4 replies
January - decision made to send question to all RMCH ward managers and medical/surgical consultants.

“Do you feel that children and young people with autism who are nursed within your clinical areas are adequately assessed for pain management issues utilising the current RMCH pain assessment tools”
Response:

- Extremely poor!!!
- 5 responded
- 2 ward managers who felt tools were adequate
- 2 clinicians who felt that the pain assessment tools failed all their patients
- 1 clinician wasn’t sure!!
April – Staff and parent/carer questionnaires via survey monkey website.

- Staff response: 43
- Parents/carer response: 8
- Poor response
## Results

### Autism Pain Management in Children & Young People
(Staff Survey) 2014/15
Royal Manchester Children’s Hospital

Total response: 43

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Do you experience problems with managing children and young people with Autism / Asperger’s?</td>
<td>35</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>81.4%</td>
<td>18.6%</td>
</tr>
<tr>
<td>2 Do you feel children and young people with Autism / Asperger’s have their pain assessed appropriately within RMCH?</td>
<td>9</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>20.9%</td>
<td>79.1%</td>
</tr>
<tr>
<td>3 Do you feel these children and young people should have a specific pain assessment tool?</td>
<td>36</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>83.7%</td>
<td>16.3%</td>
</tr>
<tr>
<td>4 Do you feel these patients would have a better pain assessment and management plan if you were to utilise a personalised assessment on admission?</td>
<td>41</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>95.3%</td>
<td>4.7%</td>
</tr>
</tbody>
</table>
## Results

### Autism Pain Management in Children & Young People
(Parent/Carer Survey) 2014/15
Royal Manchester Children’s Hospital

**Total response:** 8

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel the RMCH pain assessment approach is suitable for your child’s needs?</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>1</td>
<td>37.5%</td>
<td>12.5%</td>
<td>50%</td>
</tr>
<tr>
<td>Do you and your child understand the pain assessment tools provided at RMCH RMCH?</td>
<td>2</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>25%</td>
<td>62.5%</td>
<td>12.5%</td>
</tr>
<tr>
<td>Have you and your child been shown the RMCH pain assessment tools?</td>
<td>1</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>12.5%</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>Do you feel there should be a specific pain assessment tool for your child's individual needs?</td>
<td>5</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>62.5%</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>Are you satisfied with the management of your child’s pain during your stay in hospital at RMCH?</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>37.5%</td>
<td>37.5%</td>
<td>25%</td>
</tr>
</tbody>
</table>
Parents comments:

- “Took a long time to get doctors and nurses to understand my child’s needs and work with us”
- “Hard work, nobody understands”
- “Parents views are not readily taken on board”
- “What is the pain assessment tool?”
- “Please always speak to the parents/carers who can explain”
Scoping exercise

- Following poor response from survey monkey it was felt a scoping exercise was required.

- 13 clinical areas within RMCH included.

- All care pathways reviewed

- Only one care pathway (Burns) asked the patient/parent/carer about previous pain experiences
Audit proposal approved.

‘Pain Management in Children with Autistic Spectrum Disorder’

Consent and involvement of parents:
Patient demographics: Type of ASD?
Social skills
Speech and language
Behaviour
Parental comments
Current medication
Behaviour and mood observations post surgery
Parent/carer views
“Thank you for being warriors to do this work, you have changed our life's as parents”
“RMCH is changing our life's”
All the above were completed by parent/carer
Explanation on completion was given verbally
Audit continued

- Analgesia during operation
- Analgesia post operative (recovery/ward area)
- Vital signs
- Pain scores

These were recovered from the notes either prior to discharge or following discharge.

- A total of 51 patients have participated in this audit
- Report is currently being written up
Where are we now

- Paediatric Pain Profile Task & Finish Implementation group.
- Development of the Paediatric Pain Profile due to lack of acceptable pain assessment tools for children & young people with ASD
- April 2016 – Trial of PPP on surgical ward
- May 2016 – Trial of PPP on one of the medical wards
- Adjustment then implementation of the PPP throughout the children's division.
Actions for the future

- RMCH ward/departmental autism champions identified
- Training for nursing, medical staff and AHP’s in ASD pain assessment and management
- Publication of RMCH findings
- Re-audit
Conclusion

- Advances in the treatment of pain for children and young people with ASD have seriously been left behind than that for other children.
- There has been an urgent need to develop robust assessment measures that can be implemented into everyday clinical practice, without accurate assessment appropriate pain relief may not be provided.
- Children and young adults with ASD may not express discomfort or pain in a way that health staff understand or recognise.
- Information about the patient should include details of how they communicate pain or distress and staff should be trained to use this information and react appropriately.
References

- **Bottos S, Chambers CT.**

- **Breau LM, Burkitt C.**

- **Craig KD.**
The social communication model of pain. Can Psychol 2009: 50: 22 – 32

- **Fanurik D, Koh JL, Schmitz ML, Harrison RD, Conrad TM.**