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Pain experience, expression and coping in boys and young men with Duchenne muscular dystrophy – a pilot study using mixed methods

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#### Pain experience, expression and coping in boys and young men with Duchenne muscular dystrophy

#### Mixed methods study

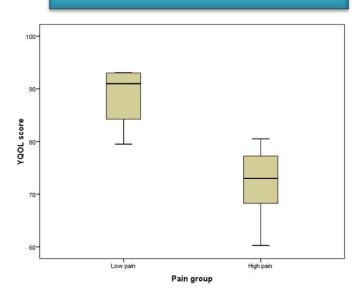
Parents' survey & instruments

Young men's interview & instruments

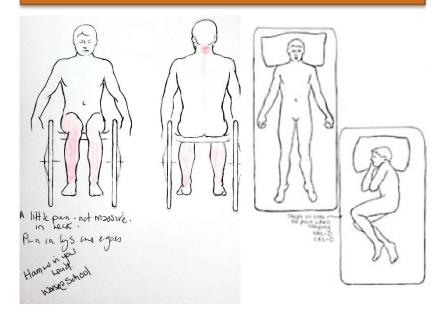
#### **Qualitative findings**

- Hurting in different places
- Telling : holding it in & letting it out
- Acting to relieve pain

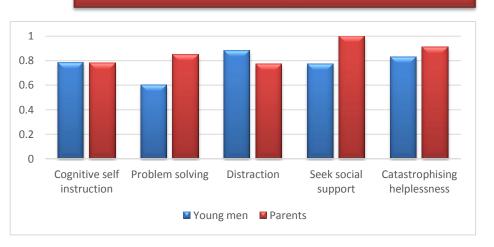
#### Impact of pain on quality of life



## Pain body map, young man (aged 11 years)



#### Ways of coping with pain (from PPCI)



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