



# My child is in pain

## developing a web-based resource for parents

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### Introduction and aims

Changes to health care delivery lead to increasing numbers of children having surgery, procedures and interventions as day-case patients, shifting the responsibility for pain management from health professionals to parents. Many parents are anxious about and insufficiently prepared to manage their child's post-operative pain and recovery. This study used a consensus approach to work with parents of children (aged 2-6 years) to develop a web-based resource to prepare and support parents managing their child's post-operative pain.

### Methods

An online survey and face-to-face and telephone interviews were undertaken with parents whose child had undergone day-case surgery.

Following thematic analysis of qualitative data and descriptive statistical analysis of quantitative data, five scenarios were developed focussing on areas of pain management that parents identified as being challenging. For example,

"I didn't know how long it takes for medicine to work and when it wears off".

"I would have liked to have known what was causing the pain as this would have helped with management and I could talk to my child about this".

Scripts were drafted and redrafted by the researchers to create storyboards linked to specifically developed illustrations. The materials were developed iteratively and consensually and then reviewed by a steering group of parents from the UK and pain experts from the UK, USA, Australia and New Zealand.

### Results

The iterative, consensual approach to the engagement of parents and professionals has ensured that every element of the resource was appropriately informed. Engagement with parents ensures it addresses their needs in a user-friendly manner. The engagement of practitioners and pain experts ensured that the resource is evidence-based and trustworthy.

We learned a number of valuable lessons during the course of this project, including:

- The researchers would have benefited from taking a crash course in website design before we embarked on this so we better understood the parameters we'd be working within.
- Working remotely was really effective.
- Engagement with parents and professionals core to success; feedback was essential
- The quality of the final resource was result of team work and the really close attention to detail by the web design team.
- Allow enough time to get it right
- The project isn't over, when it's finished! (endorsements, marketing, social media, googlemetrics)

### Discussion and conclusion

The web-based resource, 'My Child is in Pain', provides 24-hour access to five key learning scenarios to support parents in managing their child's pain after day-case surgery. Metrics are being collected on the number of hits, time spent on the site, which videos were watched, what was downloaded, links clicked, time of day and location of user (country). It has been endorsed by the Royal College of Nursing (UK) and is being recommended by practitioners in the UK, USA, Australia and New Zealand.

### References:

My Child is in Pain web resource [www.mychildispain.org.uk](http://www.mychildispain.org.uk)

Power, N.M., Howard, R. F., Wade, A.M., Franck, L.S. (2012) Pain & behaviour changes in children following surgery. Archives of Disease in Childhood. 97(10): p879-884



### Key decisions required

Decisions needed to be made about many key factors throughout the development of the resource, including:

Name of the resource	Illustrations- style, clarity etc
Content and level of content	Navigation of site
Who should do the introduction	Logos
Voice-overs (us or actors)?	Platform, accessibility
Colour schemes	Technical considerations (e.g., speed of download in UK and abroad)
Videos	

Text in the draft storyboards was reviewed for accuracy, understandability and clarity. The illustrative styles were reviewed and rated for visual appeal and resonance with the message. Video materials were developed to add depth to the resource; Parents and actors performed scripts developed from interviews with parents.



Feedback from parents and professionals has been extremely positive. Parents have commented that it is "a really easy to use and helpful site"; "It really helped the first night home when his pain was bad". Professionals have said: "a really super resource I will recommend to all our parents"; "It's now part of our discharge information leaflet".

We will continue to evaluate the resource and are planning to develop new resources focussing on meeting children's pain information needs.

