

**The information needs of children having clinical procedures in hospital: Will it hurt? Will I feel scared? What can I do to stay calm?**

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3 **The information needs of children having clinical procedures in hospital: *Will it hurt? Will I***  
4 ***feel scared? What can I do to stay calm?***  
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8 **Abstract**

9 **Background**

10 Children often have unmet information needs when attending hospital and this can cause  
11 them anxiety and uncertainty. If children are prepared and informed about what will happen  
12 during a procedure they tend to have a better experience. Finding out what children want to  
13 know before they attend hospital for procedures, could provide significant benefits for  
14 children, their families and healthcare professionals. **This study set out to investigate**  
15 **children's perspectives of what information is important and valuable to know before**  
16 **attending hospital for a planned procedure.**

17 **Methods**

18 A 'write and tell' activity sheet underpinned a semi-structured qualitative interview with  
19 children attending hospital for a planned procedure. **The interview focussed on the**  
20 **information children thought was important to know before a procedure.** Data were analysed  
21 using content analysis techniques.

22 **Results**

23 106 children aged between 8 to 12 years old participated in the interviews. The children  
24 identified **616 pieces of information they thought would be of value to children attending**  
25 **hospital for procedures.** These were **inductively coded into three types of information;**  
26 **procedural, sensory and self-regulation.** Children want to know detailed procedural and  
27 sensory information to **actively construct a script of a procedure, and then build on this with**  
28 **information about specific strategies to help them cope with and self-regulate the situation.**

29 **Conclusion**

30 **This study has identified three types of information children recognise as important in pre-**  
31 **procedural preparation. Children construct an understanding of a planned procedure through**  
32 **actively scaffolding procedural, sensory and self-regulation information.**

33 **Key Messages**

- 34 • **Children value a scaffolded approach to gaining and building up information and**  
35 **understanding about a planned procedure.**
  - 36 • **Children identify the importance of three types of information about a planned**  
37 **procedure; procedural, sensory and self-regulation information.**
  - 38 • **Children value focussed information about individual coping strategies they can use to**  
39 **help self-regulate during a procedure.**
  - 40 • **Information provided to children before a procedure needs to be individually tailored to**  
41 **each child's self-identified information needs.**
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## Introduction

Most children will attend a health care setting for a procedure at some point in their childhood (Vincent & Creteur, 2017). Health care settings are often unfamiliar to children consisting of unfamiliar people and unknown equipment. Procedures including blood tests, radiological investigations and physical examinations can cause children to experience anxiety as they are unsure what to expect (Carney et al 2006, Li et al 2016). Children and young people can feel inadequately informed about procedures (Katz, Webb, & Committee on Bioethics, 2016) and this can leave them feeling unprepared (Young et al, 2003, Fernades et al 2007), anxious and frightened (Kilkelly & Donnelly, 2011) and excluded from choices and decisions relating to their health care (Coyne, Amory, Kiernan, & Gibson, 2014). The impact of being unprepared for procedures can cause children to experience dissatisfaction and negative feelings afterwards (Bricher & Derbyshire 2005, Bray et al 2013). It can also lead to a reluctance to attend hospital in the future (Duff et al 2012).

Research has shown that a lack of child-directed information can leave children reliant on their parents to relay information to them (O'Toole, Lambert, Gallagher, Shahwan & Austin, 2016) and information relating to procedures is often written with parents in mind (Spencer & Franck 2005, Smith & Callery 2010, Wahl et al 2011, Bray & Sinha 2017). This assumes that parents will understand what will happen and know how to deliver key information to their child in a developmentally appropriate manner (Coyne et al, 2016). However, children have reported they find it difficult to gain information from their parents (Buckley & Savage 2010). While the information children want is not well understood, it is generally accepted that developmentally appropriate preparatory information has a positive effect on children's experience of clinical procedures (Jaaniste, Hayes, & Von Baeyer, 2007, Gordon et al 2010) and reduces children's anxiety (Olumide et al 2009). Research to date has focussed on evaluating interventions to prepare and educate children for surgery (Cuzzocrea et al 2013, Bok Yun et al 2015, Olumide et al 2009, Fernandes et al 2010, Tunney and Boore 2013, Shockey 2018), radiological investigations (Szeszak et al 2016, Bharti, Malhi & Khandelwal 2016) and procedures (Klassen et al 2008). Many of these interventions have been developed by adults with minimal input from children on what information should be included. We know that children can have unmet information needs (Smith & Callery 2010, Gordon et al 2010, Buckley & Savage, 2010, Keegan et al 2012, Lambert et al 2013), but despite this there has been **less focus on discovering children's perspectives on what information would be useful** before attending hospital for procedures.

**This research study sought to understand children's perceptions of what information is important for children to know before attending hospital for a planned procedure. Our investigation was not focussed on identifying the information needs of individual children, but more generally what types of pre-procedural information children consider important and**

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3 **would value.** This investigation was part of a larger study to develop and evaluate a child-  
4 centred app (Xploro) to prepare children for hospital procedures.  
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## 8 **Methods**

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### 10 **Research Design and Participants**

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14 The study used an exploratory qualitative child-centred design (Kirk 2007, Noonan et al 2016)  
15 to explore children's perspectives of information before having a planned procedure in a  
16 healthcare setting. Children were recruited from **a range of clinical departments (radiology,**  
17 **oncology ward, outpatients, day unit) within a children's hospital in the UK at different times**  
18 **and on different days of the week over a four month period.** Clinical staff were asked to  
19 identify any children and their parents who were eligible to approach to take part. The  
20 researcher introduced themselves and gave an overview of the study. The child and their  
21 parent were then left with an information leaflet and the researcher returned after a short  
22 while to ask if they would like to take part. In this way an opportunistic sampling technique  
23 (Palinkas et al, 2013) was used to recruit any eligible children aged 8 and 12 years who were  
24 undergoing a procedure such as a radiological investigation (X-rays, MRI, CT scan, ultrasound),  
25 blood test or cannulation, day surgery, oncology treatment or medical investigation. Children  
26 were excluded if they had a moderate or severe learning disability, were under the care of  
27 psychological services for procedural anxiety or did not have conversational English. **We**  
28 **hoped that by recruiting children attending hospital for a procedure, they could draw on their**  
29 **own experiences of procedural preparation and information needs as well as thinking more**  
30 **broadly about the information which would be of value for children to know.**  
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### 41 **Data collection**

42 Ethical approval was obtained by the author's University Research Ethics Committee and the  
43 Health Research Authority (HRA) (xxx identification number). The researchers were mindful  
44 of the anxiety some children can experience when attending hospital, so children and parents  
45 were approached to take part either before or after their planned procedure, depending on  
46 the needs of the child and the clinical service. All children provided assent to participate and  
47 their parent/carer provided written consent. **Interviews were conducted in a quiet area within**  
48 **the clinical department.**  
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54 **Semi-structured interviews asked children what information they thought was important for**  
55 **children to know about before a planned procedure. If a child was struggling to think of any**  
56 **information, they were prompted to think about what information *they* had wanted to know**  
57 **about before coming to the hospital for their procedure or what questions they had asked, or**  
58 **wished they had asked about their procedure.** Children chose to either tell the researcher  
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3 what they thought or write their thoughts on an activity sheet, this followed the format of  
4 'write and tell' so that information could be clarified and meanings explored (Noonan et al  
5 2016). The focussed activity sheets, including large speech bubbles, worked well in engaging  
6 children in the interview to share their thoughts and opinions (Figure 1). The layout and  
7 wording of the activity sheet was developed through consultation with five children and  
8 young people.  
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## 12 13 **Analysis**

14 The information recorded on the activity sheets was analysed using content analysis (Elo &  
15 Kyngas 2008), the questions and pieces of information identified by the children were  
16 inductively coded. The codes were then refined and grouped to form categories of the types  
17 of information valued by children. The allocation of codes was carried out independently by  
18 two members of the research team, any discrepancies were discussed, and consensus  
19 reached. We compared the types of information identified across the different genders, ages  
20 and hospital experiences of the children involved in the study.  
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## 27 **Results**

### 28 **Participant characteristics**

29 A total of 106 children (55 girls, 51 boys), with a mean age of 10.1 years participated. Seven  
30 children declined to take part. Children were attending hospital for a wide range of  
31 procedures (see table 1) and had differing experiences of hospital with 63 of the children  
32 having attended hospital before this event.  
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### 37 **Table 1 inserted here**

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40 616 pieces of information were identified by the children as important to know about before  
41 attending hospital for a planned procedure. Some children identified over ten pieces of  
42 information about a particular procedure and hospital visit while some only identified one or  
43 two pieces of information. The information the children identified was often based on their  
44 own experiences; questions they wished they had asked or information they had found out  
45 by chance that they would have found useful to know before their procedure. The children in  
46 this study had mainly relied on their parents as the main information provider.  
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51 Children's information needs were categorised into three main types of information;  
52 procedural information, sensory information and self-regulation information (see Table 2).  
53 We observed that the types of information children identified as important did not vary  
54 between different ages, genders, previous hospital experiences or between the children who  
55 were interviewed before their procedure and those interviewed afterwards.  
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6 All children identified that it was important to sequentially know procedural, then sensory  
7 information and this then led onto many of the children (n=34) acknowledging the value of  
8 self-regulation information in helping to be prepared for and cope during procedures. The  
9 information children identified as important pre-procedure, seemed to underpin a scaffolded  
10 approach to gaining information; asking questions to piece together and build up information  
11 about a planned procedure (Figure 2).  
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### 19 **Procedural Information; “What will happen?”**

20 All the children identified that it was important for children to have detailed information  
21 about a procedure (452 items). Children identified that it was important to know information  
22 around the appearance of the procedure room such as ‘*what will the room look like*’ or ‘*will*  
23 *the room be dark*’. Information around the context included ‘*how many people will be there*’  
24 and ‘*who the people will be*’. Some children also thought it was important for children to know  
25 very specific information about the environment such as, ‘*will there be a radiator?*’ they  
26 thought this would help children ‘*picture the room before they get there*’. They also  
27 highlighted that it is important for children to know about broad issues relating to a hospital  
28 visit such as what food would be available in hospital and more unusual information such as  
29 the quality of the care delivered in a hospital e.g. ‘*what standard is the hospital?*’  
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37 Every child identified the importance of information centred on knowing more about a  
38 procedure such as, ‘*what the machine does*’ or to know why a certain procedure was being  
39 undertaken ‘*why do I have to have a needle?*’ Children thought it was important to know  
40 about the equipment they may encounter such as ‘*what cannulas look like*’ or ‘*what drip*  
41 *stands are for*’. Some children also thought it was important to know the trajectory of a  
42 procedure, ‘*what will happen*’, ‘*who will you see first*’, ‘*when will it be done*’ and ‘*how long*  
43 *will it take*’. Children also identified it was important to know who would be undertaking a  
44 procedure for example, ‘*why does the nurse take blood and not the doctor*’. Children wanted  
45 honest information about what could go wrong during a procedure such as ‘*can a needle go*  
46 *right through your arm*’ and ‘*can you die?*’  
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### 53 **Sensory Information; “Will I feel scared?”**

54 The children identified that it was important to know information around the sensory aspects  
55 of a procedure (120 items), relating to what a child may experience during a procedure (touch,  
56 taste, smell, hear) and the emotions a child might feel before, during and after a procedure.  
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The piece of information children identified as most important to know about a procedure was *'will it hurt?'* The children identified this was important to know regardless of whether a child was visiting hospital for an invasive procedure such as a blood test or for a non-invasive procedure such as an X-ray. All the children who were having a blood test or insertion of a cannula identified **that it was important for children to know** whether they would experience pain. The children used words such as *'hurt', 'sharp', 'pain', 'numb'* and *'sore'* as well as *'tickle'* and *'feel weird'* to discuss how having the test or cannula could be described to other children. The children who were having surgery, mainly identified that it was most important to know about the anaesthetic and how a child may feel *'going to sleep'* or *'waking up'*. Children thought information should include details about feelings such as, *'what the gel will feel like'* (for ultrasounds), *'what the drink will taste like'* (barium for a radiological investigation), *'what the wipes will smell like'* (the alcohol wipes used before a blood test) and *'how numb feels'* (local anaesthetic cream applied for cannula insertion).

It was also **identified as important for children to be given information** around how they may feel when undergoing a procedure, such as *'will I be happy'* or *'will I feel scared?'*

### **Self-Regulation Information; "What can I do to stay calm?"**

The final theme identified information around 'self-regulation' (44 items). Not all children identified that it was important to know self-regulatory information, however those with a longer hospital stay or those undergoing more invasive treatments such as surgery or blood tests, all identified that it was useful to be provided with information about how to cope during a procedure. **They thought it was important for children to have information** about *'how to stay calm'* and how to self-distract during a procedure *'can you watch an iPad?'* It was also identified as important for children to know who would be with them to provide support during a procedure; *'can your mum stay with you', 'who else can be with you'*. It was perceived as important for children to know that they could also be supported by familiar and comforting objects such as a teddy or favourite comforter.

## **Discussion**

**This study adds an understanding of the types of information valued by children when they are visiting hospital for a planned procedure. This is important for anyone involved in developing information and resources for children and also parents and health professionals who interact with children prior to planned clinical procedures. This study was not concerned with the timing or format of information provision, which is to some extent well evidenced (Jaaniste et al 2007), but on the types or content of information children identify as important and the way children piece together or scaffold pre-procedural learning. The scaffolded approach to learning (Wood & Middleton 1975, Peterson et al 2008), recognises how information is pieced together to create a whole and deeper understanding of a particular**

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3 topic in order to problem-solve; in this instance children gaining an understanding of a  
4 planned procedure in order to cope and get through it. Scaffolding also refers to how  
5 children's learning can be facilitated by adults following children's lead (Pescoe & Gagne  
6 2017) and responding to their self-identified information needs. There is only minimal  
7 evidence within the literature which considers how children piece together or 'build up'  
8 procedural information (Jaaniste et al 2007), with the focus being on children's broader  
9 understandings of health, treatment or illness information (Coyne 2006, Smith and Callery  
10 1989). This study has demonstrated that children are competent to identify pre-procedural  
11 information needs and value being supported to actively construct this information to  
12 develop an individualised understanding of a procedure.  
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19 Children expressed that detailed pre-procedural information about who will be there (actors),  
20 the environment (scene) and what will happen (the plot) helps them develop a realistic  
21 'sequential representation' or script (Nelson 1986, Eiser 1989) of a clinical procedure. Children  
22 identified, as they have in other studies (Eiser 1989, Jaaniste et al 2007), that information  
23 needed to be detailed, specific and individualised and was less helpful if it was broad or  
24 generic. This detailed procedural information seemed to provide a basic frame for children to  
25 then build on through scaffolded exploration (Darling-Hamond 2008) to gain an  
26 understanding of sensory information, for example how a procedure may feel. This sensory  
27 information is important as procedural information alone does not have the same impact  
28 (Jaaniste et al 2007, Tak & van Bon 2006) and sensory information is important in helping  
29 children experience less stress during procedures (Armfield & Heaton 2013, Flowers & Bernie  
30 2015). Having both procedural and sensory types of information helps there be less  
31 discrepancy between what is expected during a procedure and what a child will experience  
32 (Jaaniste et al 2007, Cohen 2008).  
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41 Children's first-hand accounts from this study adds to our understanding of pre-procedural  
42 'information provision' (Jaaniste et al 2007, Gordon et al 2010) and reinforces that many  
43 children seek more than just procedural and sensory information, but also value information  
44 specifically focussed on self-regulation and coping strategies. There is some evidence to  
45 support the importance of providing children undergoing procedures with information on  
46 coping strategies (Melamed & Ridley-Johnson 1988), but currently this type of information  
47 only tends to be explored with children who have experienced difficulty during previous  
48 medical procedures (Jaaniste et al 2007). Information on self-regulation and coping was, for  
49 many children, the final building block in constructing an understanding of a planned  
50 procedure and can be seen to enable children to rehearse, plan and practice specific  
51 strategies to get through their procedure (Hockenberry et al 2011). Many of the children in  
52 this study identified that knowing and having the chance to think about and rehearse  
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3 strategies such as 'how to sit still', or 'how to stay calm' would help to develop a more  
4 meaningful or authentic script of what would happen during their procedure.  
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8 In order to build up and piece together information to develop a detailed and authentic  
9 individualised script, children need space and time to identify their own information needs.  
10 This study supports the strong evidence that children are active knowledge builders (Piaget  
11 1965, Hirsh-Pasek et al 2015) and through questioning and interaction with information  
12 sources (materials, parents and health professionals), children can build up an understanding  
13 of what will happen during a procedure, how the procedure may be experienced and  
14 strategies to help them cope or self-regulate. Interaction is important to provide children with  
15 the opportunity to reinforce their understanding of information (Hirsch-Pasek et al 2015). This  
16 study provides a useful way to consider the types of information valued by children, but it is  
17 important to recognise that each child's information needs and circumstances differ; this  
18 study demonstrated that although there was commonality in the types of information  
19 identified by as important by children there was a wide variability in the actual pieces of  
20 information or questions children thought were useful to know. The reliance on leaflets, as  
21 an information giving technique (Patel et al, 2013), without meaningful discussion, is likely to  
22 fall short of enabling children to actively construct knowledge or provide children with the  
23 sensory and self-regulation information tools they need to develop meaningful scripts. There  
24 is a need for health professionals and information developers to acknowledge the different  
25 types of pre-procedure information children value and ensure that these are addressed in a  
26 way which acknowledges children's ability to actively construct understanding and develop  
27 individualised scripts of procedures.  
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### 37 38 **Limitations**

39 This study only focussed on the information children aged 8-12 years thought was important  
40 to know before attending hospital for procedures. We recruited children who were already in  
41 hospital and were about to undergo a procedure or had already had their procedure  
42 conducted. This is likely to have influenced the information they identified as important and  
43 may be different to the information identified by children out of the hospital context.  
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### 49 **Acknowledgements (identifiable information to be added later)**

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3 **Tables**  
4

5 **Table 1: Procedure type**  
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Treatment or procedure	Total (n=106)
Radiology	26
Medical	22
Surgical	24
Blood test	20
Plaster Removal	14

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18 **Table 2. The identified information needs of children attending hospital for a planned procedure**  
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Type of information	Pieces of information identified (n=616)	Number of children identifying this type of information	Most frequently identified information needs within each type
<b>Procedural Information</b>	<b>452</b>	<b>106</b>	How long will the procedure take? What does the machine or equipment look like? Who are the different staff? How does the machine or equipment work? What will happen?
<b>Sensory Information</b>	<b>120</b>	<b>74</b>	Will the procedure hurt? How will the procedure feel? How will the medicine taste? Will I be okay? Will I be scared? How will the procedure make me feel?
<b>Self-Regulation Information</b>	<b>44</b>	<b>34</b>	Are parents allowed to stay with me? Can family visit? Who will be with me for the procedure? How can I stay calm? Can I have my iPad? Do you have to look at the screen?

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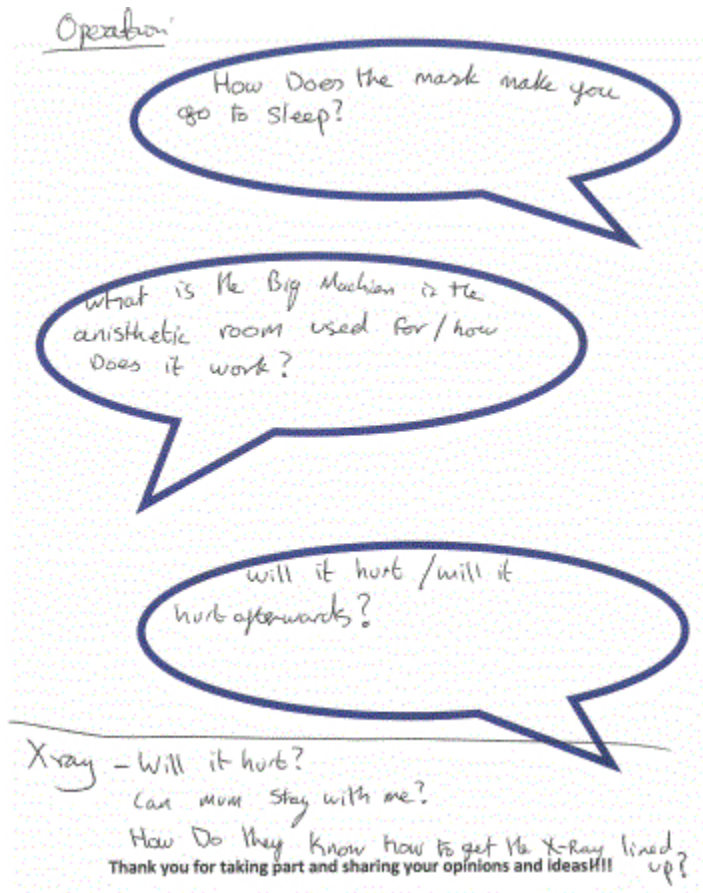


Figure 1: activity sheet

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Figure 2: Constructing an understanding of a planned procedure; procedural, sensory and self-regulation information.

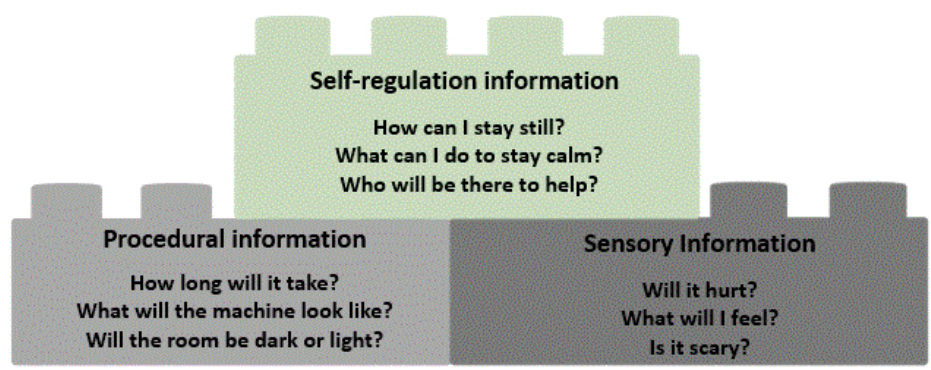


Figure 2: Constructing an understanding of a planned procedure

240x127mm (72 x 72 DPI)



Reviewer Comment	Author response
<p>I wondered about the title and subsequently the study aim and data collection etc. Is there a distinction information needs and questions asked/wanted to ask - I suppose what I am asking is whether it should be clearer that the focus of this specific manuscript appears to be classification of questions children had/asked etc. pre-procedure and this was used as basis for understanding children's information needs pre-clinical procedure? This just struck me with the use of 'will it hurt?' in the title which initially made me think this paper was about pain but it is about the questions children have pre a planned clinical procedure e.g. Will it hurt? Questions children have ....etc... It also needs to clarify this is pre-procedure, and pre-hospital admission if I am interpreting this correctly but this also needs further clarification in the methods section.</p>	<p>Thank you for your comments, these have been helpful in revisiting the paper and ensuring the focus is clear. We have amended the title so it is hopefully clearer that this paper is focussed on the different types of information children identify as important to know before a planned procedure. Our investigation was not necessarily focussed on the information needs of each individual child, but they often drew on their own experiences of questions they had wished they had asked or information they had found out by chance that they would have found useful to know before their procedure.</p>
<p>Was data collected in the hospital but asking children to retrospectively think about questions they had before admission for their planned procedure; and also was it questions they had or had asked about their procedure from parent/health care professional or through internet etc.? More detail around the data collection processes might help clarify some of these issues. It would also be useful to know more about the opportunistic sampling approach - how were children approached to take part and recruited, did any children decline. Were children approached in certain departments or for certain procedures? How was it decided who to invite/approach etc. Was it certain times of day when the researcher was present/available? It would be useful to know more details here and also for this to be reflected on for any limitations in this work and for its transferability etc. which I did not see any reference to in the discussion.</p>	<p>We have amended the methods section and added further detail to make it clearer how children were recruited and data were collected.</p>

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<p>It states children where either approached before or after their planned procedure - when and where did the interview take place? Were parents present? Were there any differences between those who took part before/after procedure in terms of impact on findings? Also I wondered as you say in the background that 'less focus has been on children's self-identified information needs before attending hospital for procedures' but if you collected data in hospital how might this have impacted on the data (dos it truly reflect before hospital?). Again these might be reflections for limitations of the work/conclusions that can be drawn.</p>	<p>Thank you for these points which have helped us clarify the methods further. We have added further detail throughout the paper which hopefully help clarify these points.</p>
<p>There were quite a lot of interviews was there a topic guide - I am just wondering if there were open ended questions about information needs or what is very direct in just exploring what questions children had and categorising these? The activity sheets (write and tell) used during interviews sounds interesting and more details on the approach used and what this added to the interview method might help to enhance the originality of this work/manuscript if some examples of that data could be shown?</p>	<p>The write and tell activity sheets underpinned the data collection process and was useful in engaging the children in the short interviews. We have included further detail in the paper and also included an example of one of the sheets (Figure 1)</p>
<p>I am a little unclear on what specific data you had to analysis did you have interview transcripts (i.e. were interviews recorded and transcribed?) and how did you analyse the activity sheets; were you just coding and categorising questions?</p>	<p>We have added further detail to the analysis section of the paper which hopefully clarifies these points.</p>
<p>A statement is made regarding influence of age, gender and procedure type - did you analysis data specifically for similarities and differences here or are you just saying you did not observe these as specific influencing factors in the questions that children ask - but perhaps this is something that requires further exploration?</p>	<p>We conducted a simple analysis on the frequency of types of information across children of different genders, ages and experience of hospital procedures. This implied that the same types of information were valued by children across the sample.</p>
<p>Under results I like this idea about questions being underpinned by a scaffold approach to gain information and also that children constructed script relating to their planned procedure can more be</p>	<p>Thank you for your comments, these have been really helpful in how we have re-visited the discussion section. We have tried to weave in some additional detail to help develop</p>

<p>1 2 3 developed around this to explain the meaning of this more <b>and</b> I know 4 you have a visual figure but could a narrative of this script as 5 described by <b>children</b> themselves be presented? This feel this would 6 help with originality of the manuscript <b>and</b> bring the data a little bit 7 beyond description of questions asked. 8 9</p>	<p>this idea, while recognising that little is written about scaffolding within children's preparation literature.</p>
<p>10 I think you need to think a little about the impact of this manuscript in 11 terms of your discussion <b>and</b> conclusion - you do draw out some 12 things around individual needs <b>and</b> different types of information 13 needs <b>and</b> how <b>children</b> develop scripts about procedures but I felt 14 some of these points needed to be more impactful as I kept asking so 15 what? <b>And</b> maybe it is so what next, now that we know this 16 about <b>children's</b> questions <b>and</b> information needs what will we do 17 with it? You mentioned at outset that this is to inform a larger study 18 maybe there is an opportunity to bring forward recommendations for 19 future work <b>and/or</b> how this work will inform the larger study? 20 21</p>	<p>Thank you for these comments, we have re-visited the discussion and amended it to hopefully make the papers contribution to our understanding of children's information needs clearer.</p>
<p>22 In key messages you state that <b>children</b> had unmet needs but so this 23 study asked <b>children</b> what questions they had, what questions they 24 wanted to ask <b>and</b> what they had asked - so in some cases 25 e.g. <b>children</b> had asked questions were their information needs met? I 26 am not sure if you looked at that - whether <b>children</b> who had asked 27 questions were satisfied with the information they received that it 28 met their needs? Again it might be just to be clear on what the 29 specific conclusions are <b>and</b> what you can definitely say they are 30 within the limits of the data set you have. Same point related to bullet 31 point 3. 32 33</p>	<p>Hopefully this has been addressed in the earlier amendments to the focus of the research study and data collection.</p>