PEER REVIEW HISTORY

BMJ Paediatrics Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Delivery of the UN Convention of the Rights of the Child in an acute paediatric setting; an audit of information available and service gap analysis
AUTHORS	Przybylska, Marianna; Burke, Niall; Harris, Clare; Kazmierczyk, Marcel; Kenton, Eleanor; Yu, Olivia; Coleman, Harriet; Joseph, Sonia

VERSION 1 – REVIEW

REVIEWER	Reviewer name: Bob Phillips Institution and Country: University of York, UK Competing interests: None
REVIEW RETURNED	28-Jan-2019

GENERAL COMMENTS	MAJOR This paper is a report of a simple interview, observation and resource-assessment undertaken at a large Children's Hospital in Scotland. It uses an unvalidated scale to assess resources, with no clear evidence of replicability (internally or externally). The paper describes observations of pre-assessment clinics for planned admissions, but is described as a paper examining the information needs and the satisfaction of those via acute admission (via ED or direct referral). The paper doesn't describe the way these different sources of information are compared or contrasted, or any underlying explanations as to how the resources discovered may have emerged, and potentially their varied roles within pay-for and national-insurance based health care settings. The methods section does not detail who undertook the assessments, if there was any degree of agreement assessed, or re-test validity. The use of interviews and observations of pre-attendance clinics seems at odds with the earlier description of information about emergency admission, as do the questions to the play staff about these resources. These varied elements of why and how a child and family arrive, the different expectations and needs, and considerations of possible solutions don't really appear to be clearly threaded through the report. The proposal for a greater development of the individual hospital provision of general health information (red flags, safety netting) should be thought about again, alongside the consideration of wasted resource as each unit would then be intended to replicate this. Perhaps such advice would be better provided by signposting a national/UK-wide resource (such as NHS Choices, or an RCPCH information source?). The local hospital specifics – WiFi, food and parking – would then be perhaps clearer. MINOR P6 L53 Multisystem disease – I think this means it's not a single system (e.g. cardiology) unit – rather than the patients have multisystem diseases (like LCH). Can this be clarified and maybe rephrased?

	P7 L15 Systematic comparison cf the abstract 'systematic review'. The former phrase appears more appropriate – the latter tends to a specific type of evidence synthesis (for example – Cochrane Collaboration reviews). Would be better to use this in the abstract.

REVIEWER	Reviewer name: Samantha Armitage Institution and Country: Sheffield Children's NHS Foundation Trust, UK Competing interests: None to declare.
REVIEW RETURNED	13-Feb-2019

GENERAL COMMENTS	Thank you for submitting this paper which is described as an evaluation of information needs and resources in children's acute services. NHS services tend to rely on giving information to support clinical care, often without much consideration of the quality or effectiveness of such practice. Exploring this topic is therefore of interest and importance but some considerations for the manuscript: The method is not specified as an audit until page 10. It would be helpful for this to be specified in the title, abstract and introduction for clarity. The interviews and observations are a service evaluation of patient experience rather than audit. Presenting the audit as an audit cycle would be helpful: 1) selecting a clinical practice standard, 2) measuring current practice in terms of the target behaviour, 3) feeding back, 4) using the feedback. 1)　　Online materials and resources for children have been evaluated against specified categories e.g. location, local area, team demographics, feedback (websites), format, interactivity level (child specific resources). It is not clear if these are evidence-based standards or how these categories/standards were determined as important in the context of children's information needs. Some standards e.g. interactivity level need specifying further – what does this mean? Colouring in, writing down, reading level? 2)　　Current practice regarding information resources and websites were measured. The paper suggests the 'amount' of information for each category was the measure and 'amount' was counted and scored. My understanding is the more information in the category the higher the score? It's not clear how 'information' was counted nor why simply the volume of information is key – can you have too much information? 3)　　Feedback mechanisms are not discussed e.g. to play specialists 4)　　There are brief statements about using the audit and service evaluation data to improve local information resources but this is not well explained. The paper would benefit from a clear and consistent message about why information is important and the role it plays in health/healthcare. Currently, the paper reports information is important for: empowerment, involvement, autonomy, decision making, stress, anxiety and satisfaction with services. Clarity and consistency about the pathway from information to your chosen outcome (e.g. children's decision-making) and the part that information plays in this pathway (e.g. increasing children's knowledge) would be beneficial, especially in the introduction and discussion.

	The paper would benefit from a focused thread throughout to pull all the data together e.g. if the focus is children's decision-making, it would be helpful to the reader to report the interview questions and observations linked to this specifically, and to focus results on this. Presenting the parent data contradicts some of the arguments made in the introduction about professionals focusing on parent views, not children's - but this depends on where you want the focus to be.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

MAJOR

This paper is a report of a simple interview, observation and resource-assessment undertaken at a large Children's Hospital in Scotland.

It uses an unvalidated scale to assess resources, with no clear evidence of replicability (internally or externally).

Author's response: We agree with the reviewer that the methodology used to review resources was not validated externally. However, our aim was not to formally compare different resources nor conclude which one was better, but to extract information on what topics are addressed and how. We believe that in this case it was appropriate to use an unvalidated scale. Nevertheless, we have now added more explanation in the Methods section (page 11-12) describing how the resources were evaluated. For the child-specific resources, we only provide a structured summary of each resource (Table 2). The website review was conducted using pre-defined criteria (details are now presented in Supplementary Table 2) by two students (MP and EK) and any discrepancies were discussed with the consultant reviewer (SJ).

The paper describes observations of pre-assessment clinics for planned admissions, but is described as a paper examining the information needs and the satisfaction of those via acute admission (via ED or direct referral).

Author's response: Clarifications and justification of the methodology used have been added on page 7, line 17-36. Our study was an audit of information provided to children admitted acutely and their families in comparison to those requiring planned surgical admission, therefore we needed to assess resources available for both types of admissions.

The paper doesn't describe the way these different sources of information are compared or contrasted, or any underlying explanations as to how the resources discovered may have emerged, and potentially their varied roles within pay-for and national-insurance based health care settings.

Author's response: The methodology section has been expanded to provide more information on the review process.

We would like to thank the reviewer for pointing out this omission. We have added the following paragraph to the discussion to address the potential impact of different healthcare systems on hospital resources: "High quality resources were predominantly from privatised healthcare settings, such as the United States. For these hospitals, the websites may be a source of marketing, promotion and income in addition to providing practical process information. Additionally, patients who pay for their care, either directly or through insurance, may have higher expectations on the quality of service information provided" (page 17, lines 31-41).

The methods section does not detail who undertook the assessments, if there was any degree of agreement assessed, or re-test validity.

Author's response: We have made changes to clarify that the same group of medical students were involved in 'process observations', interviews, and evaluation of child-specific resources and hospital websites. Methodology section has also been updated to provide more detail on the review process. Re-test validity was not evaluated since evaluation of the resources was only conducted for information gathering purposes.

The use of interviews and observations of pre-attendence clinics seems at odds with the earlier description of information about emergency admission, as do the questions to the play staff about these resources.

Author's response: We have added the following justification of the methodology used (page 7, line 17-36): "Our study had three aims. First, to audit the information currently given to children and families requiring planned surgical admissions in comparison to those admitted acutely to medical paediatric inpatients, enabling clear definition of the "information gap" within our in-patient service. Secondly, to identify examples of child-specific information resources nationally and internationally. The final aim was to triangulate detailed qualitative feedback from the experience and understanding of children admitted acutely to that of their parents and of the play specialists who routinely support the planned admission as well as the acute admission service. The hope was this whole service analysis would enable reflection and attainment of delivery of Article 17 of CRC."

These varied elements of why and how a child and family arrive, the different expectations and needs, and considerations of possible solutions don't really appear to be clearly threaded through the report.

Author's response: We thank the reviewer for this comment. We have made changes throughout the manuscript to address this point, in particular:

1.   Introduction - added consideration of the unique opportunity that acute admission care offers to engage children in healthcare (page 5, lines 41-50), expanded on the current views and expectations children have of the healthcare service (page 6, lines 3-12) and discuss the importance of considering different information needs of patients based on personal circumstance and how these may be barriers to inclusion (page 6, lines 15-17).

2.   Methodology – details of admissions and need to consider patient factors, e.g. clinical need and length of stay (page 6-7, lines 52-12)

3.   Discussion - consideration of possible solutions: role of health literacy responsive organisations (page 17, lines 15-22), development of standardised national resources (page 17, lines 45-55), factors that need to be considered prior to resource development (page 18, lines 3-9). In our "outcomes and conclusion" section, we discuss the local outcome of our study, and the resource development at our study site (page 18-19, lines 43-6).

The proposal for a greater development of the individual hospital provision of general health information (red flags, safety netting) should be thought about again, alongside the consideration of wasted resource as each unit would then be intended to replicate this. Perhaps such advice would be better provided by signposting a national/UK-wide resource (such as NHS Choices, or an RCPCH information source?). The local hospital specifics – WiFi, food and parking – would then be perhaps clearer.

Author's response: We would like to thank the reviewer for pointing out that it would be of value to consider the implications of our findings on a greater scale. We have restructured our discussion to first consider the issue from a wider perspective, considering the role of health literacy responsive organisations (page 17, lines 15-22), benefits of developing standardised national resources (page

17, lines 45-55), and factors that need to be considered prior to resource development (page 18, lines 3-9). In our "outcomes and conclusion" section, we discuss the local outcome of our study, and the resource development at our study site (page 18-19, lines 43-6).

MINOR

P6 L53

Multisystem disease – I think this means it's not a single system (e.g. cardiology) unit – rather than the patients have multisystem diseases (like LCH). Can this be clarified and maybe rephrased?

Author's response: We thank the reviewer for this comment and have rewritten this sentence.

P7 L15

Systematic comparison cf the abstract 'systematic review'. The former phrase appears more appropriate – the latter tends to a specific type of evidence synthesis (for example – Cochrane Collaboration reviews). Would be better to use this in the abstract.

Author's response: We agree with the reviewer and have changed wording to systematic comparison.

Reviewer: 2

Thank you for submitting this paper which is described as an evaluation of information needs and resources in children's acute services. NHS services tend to rely on giving information to support clinical care, often without much consideration of the quality or effectiveness of such practice. Exploring this topic is therefore of interest and importance but some considerations for the manuscript:

Author's response: We would like to thank the reviewer for acknowledgement of our work.

The method is not specified as an audit until page 10. It would be helpful for this to be specified in the title, abstract and introduction for clarity. The interviews and observations are a service evaluation of patient experience rather than audit.

Author's response: Our study aimed to assess the gap between resources available to children acutely admitted and resources available to children requiring planned surgical admissions. We have now specified our study as an audit in the title, abstract, study aims (page 7, lines 17-36) and methodology. We have also restructured our discussion so the study findings are considered with this focus in mind.

Presenting the audit as an audit cycle would be helpful: 1) selecting a clinical practice standard, 2) measuring current practice in terms of the target behaviour, 3) feeding back, 4) using the feedback.

Author's response: We have restructured our article to more clearly present the audit cycle. In the introduction, we outline the evidence base behind the standard assessed - the recommendations of United Nations Convention on the Rights of the Child (CRC), reports highlighting more work is still required to adhere to CRC and discussion of the focus of previous efforts being planned admission for surgery. In our methodology, we justify the methods used (page 7) and state that we will be comparing the information provided to acutely admitted patients to those undergoing planned admission for surgery. In our "outcomes and conclusion" section (page 18) we have added a paragraph discussing the feeding back of our study findings and how we have used the feedback to implement change locally.

1) Online materials and resources for children have been evaluated against specified categories e.g. location, local area, team demographics, feedback (websites), format, interactivity level (child specific resources). It is not clear if these are evidence-based standards or how these categories/standards were determined as important in the context of children's information needs. Some standards e.g. interactivity level need specifying further – what does this mean? Colouring in, writing down, reading level?

Author's response: We thank the reviewer for this comment, and agree that the criteria that resources and websites were evaluated against were not evidence-based standards. However, the criteria were selected based on information categories highlighted as important in the parent and paediatric patient interviews. We have added clarifications on page 11, lines 5-43, and provide details of the evaluation criteria in Supplementary Table 2. We have also added a definition of interactivity level (page 12, lines 6-8) into methods and as a footnote in Table 2.

2) Current practice regarding information resources and websites were measured. The paper suggests the 'amount' of information for each category was the measure and 'amount' was counted and scored. My understanding is the more information in the category the higher the score? It's not clear how 'information' was counted nor why simply the volume of information is key – can you have too much information?

Author's response: We have now included Supplementary Table 2 which provides detailed information on the category-specific criteria used to assess the hospital websites.

3) Feedback mechanisms are not discussed e.g. to play specialists

Author's response: We have added discussion of feedback mechanisms to staff and the outcome of our audit on page 18-19, lines 31-6.

4) There are brief statements about using the audit and service evaluation data to improve local information resources but this is not well explained.

Author's response: Discussion has been restructured to clarify the implications of our findings. We now consider the role of health literacy responsive organisations (page 17, lines 15-22), benefits of developing standardised national resources (page 17, lines 45-55), and factors that need to be considered prior to resource development (pages 18, lines 3-9). In our "outcomes and conclusion" section, we discuss the local outcome of our study, and the resource development at our study site (page 18-19, lines 43-6).

The paper would benefit from a clear and consistent message about why information is important and the role it plays in health/healthcare. Currently, the paper reports information is important for: empowerment, involvement, autonomy, decision making, stress, anxiety and satisfaction with services. Clarity and consistency about the pathway from information to your chosen outcome (e.g. children's decision-making) and the part that information plays in this pathway (e.g. increasing children's knowledge) would be beneficial, especially in the introduction and discussion.

Author's response: Significant portions of our introduction and discussion have been restructured to provide a clearer message and stronger narrative. Our focus has been clarified as adherence to the recommendations of the United Nations Convention on the Rights of the Child.

The paper would benefit from a focused thread throughout to pull all the data together e.g. if the focus is children's decision-making, it would be helpful to the reader to report the interview questions and observations linked to this specifically, and to focus results on this.

Author's response: Significant changes and restructuring have been done to provide a clearer message with the main focus considered to be adherence to the United Nations Convention on the Rights of the Child, in particular ensuring children are provided with sufficient age appropriate information. Methodology and Table 1 have been edited and results have been restructured to present findings in terms of topics covered, instead of by interview series. We first present the results of the audit of study site resources, and then present results from the interviews. Description of the interviews has been restructured to discuss the views of children, parents and play specialists on child-specific resources (page 13, lines 3-22) and then parents experience of acute admissions and their information needs (page 13, lines 26-48).

Presenting the parent data contradicts some of the arguments made in the introduction about professionals focusing on parent views, not children's - but this depends on where you want the focus to be.

Author's response: We have decided to focus on the views of paediatric patients, their families and play specialists as all three groups are centrally involved in the study unit, and therefore for a complete review input from all needs to be considered.