

## 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

<b>TITLE (PROVISIONAL)</b>	Quantifying the costs of hospital admission for families of children with a febrile illness in the North East of England
<b>AUTHORS</b>	van der Velden, Fabian Lim, Emma Smith, Holly Walsh, Rebecca Emonts, Marieke

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Dr. Virginia Mumford Macquarie University Faculty of Medicine Health and Human Sciences Australian Institute of Health Innovation L6, 75 Talavera Road Sydney New South Wales 2109 Australia
<b>REVIEW RETURNED</b>	09-Jan-2024

<b>GENERAL COMMENTS</b>	<p>Quantifying the costs of hospital admission for families of children with a febrile illness in the North East of England</p> <p>Thank you for asking me to review this paper on OOP costs where the authors present a study on the impact of a child's hospital visit. Although an important topic I feel the paper needs additional work in terms of defining the issue, elaborating on certain aspects of the methods, and in justifying some claims in the discussion.</p> <p>In the introduction I think it is worth reiterating that these are non-medical OOP costs as many studies researching OOP costs in paediatric cancer are based in the US and include medical costs. L90 etc discusses studies where medical costs are mixed in with non-medical costs which would cause confusion for readers. I recommend defining the non-medical OOP costs and then comparing this to studies that included medical OOP costs as the two are not comparable (refs 7&amp;8).</p> <p>L42I was interested in the statement that paediatric admissions can be expensive – again this seems incomplete – paediatric versus adult admissions? Cost of care vs OOP?</p> <p>L73 “In the first year post-diagnosis, families of paediatric cancer patients reported non-medical costs ranging 0.2%-283% of their families' annual income” I could not find this reference in the paper.</p> <p>L106 Please detail how the two groups were defined and differentiated – this is not detailed here or in the results</p> <p>L187 the loss of earnings can be difficult to estimate, perhaps the authors should consider a more societal approach by using national incomes and oncosts to get a true burden? Likewise with childcare costs which do not capture the voluntary costs of friends and neighbours (L224). The authors could compare this to the costs</p>
-------------------------	--

	<p>collected in the study especially in terms of the impact statements from families</p> <p>L239 the authors state the “hospitals have a responsibility to mitigate the burden of a child’s hospitalisation” without discussing why this should be the case rather other funding bodies (social services etc)</p> <p>L246 The authors state that a “policy of feeding all resident parents is a basic right “ but this is not how this is portrayed in the International Covenant – which is aimed at recognizing the right for everyone. However, I do like the focus on discharge care.</p> <p>L273 need to compare with regional or national averages</p> <p>I think the authors need to make a much better case for why hospitals should be responsible for the social services aspects of the families in their care when there are other agencies tasked with this important function</p> <p>I also question the use of self-reported income loss as it would make the results more translatable to use a productivity costs based approach</p> <p>L273 this section states that the survey participants were from a broad sample of families in terms of, underlying illness, chronic disease, geographical location, admission duration, frequency and family size. However, Table 1 does not put this into perspective of the broader population or include details of family size and location.</p> <p>Do the authors have any data from the final question in the survey?</p>
--	--

<b>REVIEWER</b>	Dr. Damian Roland University of Leicester Health Sciences Princess Road West Leicester LE1 7RH United Kingdom of Great Britain and Northern Ireland
<b>REVIEW RETURNED</b>	06-Feb-2024

<b>GENERAL COMMENTS</b>	<p>This is a much needed and well written paper. I think the design, if a little exploratory, is sound and will be of interest to a wide range of paediatricians. I am personally surprised the costs weren't higher. I'm wondering if an estimate can be made of the how much the costs were out of an average persons daily expenditure?</p> <p>Sorry if I missed this - Why are two groups mentioned and what was the difference between the groups?</p> <p>Over what time periods were the surveys handed out?</p>
-------------------------	--

### VERSION 1 – AUTHOR RESPONSE

Dear Dr Guddi Singh and Dr Shanti Raman, and reviewers Dr Mumford and Dr Roland,

Thank you on behalf of all authors for your time and efforts to review our manuscript.

We greatly appreciated your comments which allowed us to further improve the quality and content of our manuscript for publication.

We have now revised our manuscript and kindly refer you to our detailed point-by-point response to your individual feedback.

Please do not hesitate to contact us for any further queries, we are happy to elaborate further.

Yours faithfully, on behalf of the authors

Emma Lim  
Fabian van der Velden

Point-by-point response to the reviewer's comments

Formatting Amendments

1) Figure/s should not be embedded

Please remove all your figures in your main document and upload each of them separately under file designation 'Image' (except tables and please ensure that figures are in better quality or not pixelated when zoomed in).

They can be in TIFF, JPG, PNG or PDF format. Make sure that they have a resolution of at least 300 dpi and at least 90mm x 90mm of width. Figures in document, excel and PowerPoint format are not acceptable.

- We have removed the figures from the main document and uploaded these separately

2) Reference citation format

References must be numbered sequentially as they appear in text. References numbers in the text must be inserted immediately after punctuation (with no word spacing)- for example, [6] not [ 6 ].

Where more than one reference is cited, separated by a comma- for example, [1, 4, 39].

For sequences of consecutive numbers, give the first and last number of the sequence separated by a hyphen- for example, [22-25]. References provided in this format are translated during the production process to superscript type, which act as hyperlinks from the text to the quoted references in electronic format of the article.

Please note, if your references are not cited in order in your article will be returned to you before acceptance for correct ordering. Please visit the link below for further information:

<http://group.bmj.com/products/journals/instructions-for-authors/formatting#references>

- The references have been updated to the requested formatting output style

3) Funding Information Mismatch

Please ensure that the funding statement in the submission system and main document are the same.

- The funding statements are now matching in the submission system and the main document

4) Different Authors Name Format

The author's name format on the system and the main document file is different. "Fabian J.S. van der Velden" in the main document while "van der Velden, Fabian Johannes Stanislaus" in the system. The names indicated in the main text must match the name registered in the ScholarOne submission system.

- The name in the main text now matches the name registered in the ScholarOne submission system, i.e. Fabian Johannes Stanislaus van der Velden.

5) Supplementary File Format

Please be advised that supplemental materials and appendices included with the manuscript must be uploaded in PDF format. Kindly convert the supplemental file/s in the submission to PDF and re-upload.

- All supplementary files have been converted to PDFs and have been re-uploaded to the submission system.

Reviewer 1, Dr Virginia Mumford.

Quantifying the costs of hospital admission for families of children with a febrile illness in the North East of England

Thank you for asking me to review this paper on OOP costs where the authors present a study on the impact of

a child's hospital visit. Although an important topic I feel the paper needs additional work in terms of defining the issue, elaborating on certain aspects of the methods, and in justifying some claims in the discussion.

In the introduction I think it is worth reiterating that these are non-medical OOP costs as many studies researching OOP costs in paediatric cancer are based in the US and include medical costs.

- Thank you for this comment, we have clarified what non-medical out-of-pockets costs are in more detail in lines 69-74. We added further clarification on the studies on out-of-pocket costs mainly originating from the US and including both medical and non-medical out-of-pocket costs (lines 78-83)

L90 etc discusses studies where medical costs are mixed in with non-medical costs which would cause confusion for readers. I recommend defining the non-medical OOP costs and then comparing this to studies that included medical OOP costs as the two are not comparable (refs 7&8).

- We have clarified that the costs from the studies were referred to were medical and/or non-medical with regards to the source study in the reference (lines 83-86)

L42I was interested in the statement that paediatric admissions can be expensive – again this seems incomplete – paediatric versus adult admissions? Cost of care vs OOP?

- We elaborated on this clarifying more clearly that this refers to non-medical out-of-pocket costs (line 44)

L73 "In the first year post-diagnosis, families of paediatric cancer patients reported non-medical costs ranging 0.2%-283% of their families' annual income" I could not find this reference in the paper.

- Thank you for this comment. The sentence has been rephrased and reflects better what was stated in the referenced original study from Russel et al. 2013

L106 Please detail how the two groups were defined and differentiated – this is not detailed here or in the results

- In the results we did not define between two groups, we aimed to show that we did not exclusively distribute the survey among immunocompetent febrile children, but also included immunocompromised febrile children in our cohort, the latter whom are often excluded from studies like these. We have rephrased this now more clearly (lines 125-127)

L187 the loss of earnings can be difficult to estimate, perhaps the authors should consider a more societal approach by using national incomes and oncosts to get a true burden?

Likewise with childcare costs which do not capture the voluntary costs of friends and neighbours (L224). The authors could compare this to the costs collected in the study especially in terms of the impact statements from families

- Thank you for this comment. We have considered a societal approach and using national incomes as a means to better identify the burden of loss of earnings and would consider using this in the future. We wanted to focus on patient reported outcomes including loss of earnings in this instance. Additionally, in our regions there is a high-number of self-employed casual labourers, and labourers working on zero-hour contracts, which might be under-represented when using national data in our analysis. Using two-thirds of the UK median hourly pay as a measure for low pay, 13% of employees in the UK were in low-pay employment. In Wales, the proportion of employees in low pay was 17%, compared with 11% in Scotland and 14% in Northern Ireland. In our region in the North East of England this is 19%.

L239 the authors state the "hospitals have a responsibility to mitigate the burden of a child's hospitalisation" without discussing why this should be the case rather other funding bodies (social services etc)

- Thank you for this comment, we agree that this required further elaboration and we should have mentioned other funding bodies more specifically tasked with mitigating these burdens. We have rephrased and elaborated on this in lines 256-258

L246 The authors state that a "policy of feeding all resident parents is a basic right " but this is not how this is portrayed in the International Covenant – which is aimed at recognizing the right for everyone. However, I do like the focus on discharge care.

- Thank you for this comment. Following discussions amongst the authors, review of the International

Covenant we decided to remove this statement from the discussion as we had incorrectly paraphrased it, and kept our statements regarding discharge care.

L273 need to compare with regional or national averages

- We have now added these data to provide further argument to this statement on food and fuel poverty in lines 237-238, 260-261, 273-275, and 277-282

I think the authors need to make a much better case for why hospitals should be responsible for the social services aspects of the families in their care when there are other agencies tasked with this important function

- We have added a statement and data from an internal quality improvement project that has been conducted in our hospitals surrounding providing meals for parents in hospital to further the case for why hospitals need to play a role in providing some services (lines 278-283) whilst they are in patients and agree that a joined up hospital and social care approach is needed.

I also question the use of self-reported income loss as it would make the results more translatable to use a productivity costs based approach

- We agree that a productivity costs-based approach would make our exploratory work more translatable and this method (Zhang W, Anis AH, 2014, PMID 24639039) has been used in previous work by yourself (Mumford V et al., 2018, PMID 29671913). However we did not conduct a census survey, and our region does not reflect the national average. Hence we chose to utilise self-reported income loss, a method previously developed in collaboration with Newcastle University and used to measure out-of-pocket costs in adult colorectal cancer (Ó Céilleachair et al., 2017 PMID 28341973).

L273 this section states that the survey participants were from a broad sample of families in terms of, underlying illness, chronic disease, geographical location, admission duration, frequency and family size. However, Table 1 does not put this into perspective of the broader population or include details of family size and location.

- We have adjusted the text in this line to reflect the data presented in Table 1, and added a figure to demonstrate the geographical distribution of patients in our region

Do the authors have any data from the final question in the survey?

- We did have some data from the final question in the survey. The largest other cost that was reported or mentioned by families were costs for entertainment. We added some of this data in the results section

Reviewer 2: Dr. Damian Roland

This is a much needed and well written paper. I think the design, if a little exploratory, is sound and will be of interest to a wide range of paediatricians. I am personally surprised the costs weren't higher. I'm wondering if an estimate can be made of the how much the costs were out of an average persons daily expenditure?

- This is a good point. When we wrote the draft the UK 2021 Census Data were not yet available. These have since been published by the Government. We have now got contemporaneous data on the average weekly household expenditure and added a statement that a one-week admission would cost approximately three-quarters of an average week household expenditure. (lines 233-236)

Sorry if I missed this - Why are two groups mentioned and what was the difference between the groups?

- In the first draft of this paper we aimed to look at immunocompromised and immunocompetent febrile children as separate groups. However based on previous reviewer comments, we felt that we did not have sufficient power to do so, and took on their suggestion to report our study as one group of febrile children (as they present to A&E in a similar manner). This has been adjusted in the revision (lines 125-127)

Over what time periods were the surveys handed out?

- The surveys were handed out between March and November 2022, as stated in the methods (line 107)

<b>REVIEWER</b>	Dr. Virginia Mumford Macquarie University Faculty of Medicine Health and Human Sciences Australian Institute of Health Innovation L6, 75 Talavera Road Sydney New South Wales 2109 Australia
<b>REVIEW RETURNED</b>	11-Apr-2024

<b>GENERAL COMMENTS</b>	<p>Thank you for asking me to review this study again. This study is important as it addresses a real issue over access to care for those on lower incomes and I appreciate the work that the authors have done to address my comments. However, I feel there are some outstanding issues that have not been addressed.</p> <p>1) L189 Direct loss of earnings costs - I feel asking this question in terms of what the parent has experienced in terms of loss of earnings is not representative of the true cost. Using a societal approach is more inclusive as it values time whether the parent is working or not – and if working does not address who is covering while this person is away – ie the productivity cost is not being addressed. It also places a higher value on higher earning individuals but this is not representative or scalable unless a wide range salaries are covered. For employees, rather than self-employed individuals, the full costs (ie salary plus on-costs need to be included. The authors do not seem to fully consider the costs for other caregivers.</p> <p>2) P247 The responsibility of hospitals. The author have still not given a coherent reason why these incidental costs are the responsibility of the hospital - whose job is to provide care irrespective of the ability to pay. The hospitals' role in providing additional care services is not addressed in terms of whether these additional costs should be met from a hospital's clinical care budget, rather than the social care budgets.</p>
-------------------------	---

<b>REVIEWER</b>	Dr. Damian Roland University of Leicester Health Sciences Princess Road West Leicester LE1 7RH United Kingdom of Great Britain and Northern Ireland
<b>REVIEW RETURNED</b>	28-Mar-2024

<b>GENERAL COMMENTS</b>	Many thanks for the responding the comments of the reviewers. I think the additional data on average income frames the amount spent during a hospital admission very well.
-------------------------	--

### VERSION 2 – AUTHOR RESPONSE

Dear editors Dr Guddi Singh and Dr Shanti Raman, and reviewers Dr Mumford and Dr Roland,

Thank you for the invitation to provide a further minor revision to our manuscript 'Quantifying the costs of hospital admission for families of children with a febrile illness in the North East of England'.

We would like to thank the reviewers for their constructive comments and we are keen to submit our revised manuscript for your consideration.

Please find our responses to the reviewers comments below.

Kind regards, on behalf of the authors

Dr Fabian van der Velden

Dr Emma Lim

#### Comments from the editors

1. Using a societal approach is more inclusive as it values time whether the parent is working or not – and if working does not address who is covering while this person is away – ie the productivity cost is not being addressed. So perhaps 1 sentence acknowledging the broader costs to the family and society, whether the parent is in paid employment or not.

- Thank you for this comment. We have added a sentence to the limitations section of the discussion [lines 314-319]

2. P247 The responsibility of hospitals. Perhaps acknowledge that healthcare services may not be able to respond to patients' financial constraints, but that health workers and the healthcare system have an ethical obligation to respond to the social determinants of health, which so clearly impact on health outcomes.

- Thank you, we have added a regarding this to the discussion [Lines 259-263]

Associate Editor

#### Comments to the Author:

I am keen to publish this piece, but I need you to please try to make some commentary addressing Reviewer 2's critiques which are more systemic and reflect the way services are structured and financed more than anything else.

- Thank you we agree with the importance of reflecting systemic and international differences in healthcare systems funding. Please see our responses to reviewer 2's critiques below for how we addressed this in the revised manuscript

#### Comments from the reviewers

Reviewer: 1

Dr. Damian Roland, University of Leicester, University Hospitals of Leicester NHS Trust

#### Comments to the Author

Many thanks for the responding the comments of the reviewers. I think the additional data on average income frames the amount spent during a hospital admission very well.

- No further action was required based on the their comments, thank you

Reviewer: 2

Dr. Virginia Mumford, Macquarie University Faculty of Medicine Health and Human Sciences

#### Comments to the Author

Thank you for asking me to review this study again. This study is important as it addresses a real issue over access to care for those on lower incomes and I appreciate

the work that the authors have done to address my comments. However, I feel there are some outstanding issues that have not been addressed.

1) L189 Direct loss of earnings costs - I feel asking this question in terms of what the parent has experienced in terms of loss of earnings is not representative of the true cost. Using a societal approach is more inclusive as it values time whether the parent is working or not – and if working does not address who is covering while this person is away – ie the productivity cost is not being addressed. It also places a higher value on higher earning individuals but this is not representative or scalable unless a wide range salaries are covered. For employees, rather than self-employed individuals, the full costs (ie salary plus on-costs need to be included. The authors do not seem to fully consider the costs for other caregivers.

- Thank you for this valid comment. While we recognise a societal approach is more inclusive as per the arguments provided by the reviewer, particularly the value of time, these data were unavailable to us, unfortunately. Hence, we chose to use patient-reported values, which previously have proven to be a useful and valid method to report these kind of costs as well [Iragorri et al. 2021]. In our survey (supplementary file 2) we did ask those families reporting loss of earnings for: the parent in-hospital, the parent not in hospital, the patient themselves, other family member(s), and any other(s) involved with the family, which were pooled to provide the overall Loss of Earnings. Although this might still not fully consider the true total costs for other caregivers, we did consider this in our survey design. We have added a statement in this regard to our limitations section in the discussion. [lines 314-319]

2) P247 The responsibility of hospitals. The author have still not given a coherent reason why these incidental costs are the responsibility of the hospital - whose job is to provide care irrespective of the ability to pay. The hospitals' role in providing additional care services is not addressed in terms of whether these additional costs should be met from a hospital's clinical care budget, rather than the social care budgets.

- Thank you for this comment. While the hospital system is not expected to cover the costs incurred by families, nor financed to do so, it has an ethical obligation to minimise these costs by signposting to social care and council services. Social prescribing link workers are employed in the UK to provide better links between hospital and social care and ensure families-in-need access all the aid and benefits available to them. We added this clarification to the discussion [lines 259-263]