

## 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>	What constitutes successful commissioning of transition from children's to adult services for young people with long-term conditions, and what are the challenges? An interview study
<b>AUTHORS</b>	Kolehmainen, Niina; McCafferty, Sara; Maniatopoulos, Gregory; Vale, Luke; Le-Couteur, Ann; Colver, Allan

### VERSION 1 - REVIEW

<b>REVIEWER</b>	Cass, Hilary Evelina London Children's Hospital UK Competing interests: None
<b>REVIEW RETURNED</b>	25-May-2017

<b>GENERAL COMMENTS</b>	<p>This is a very well conducted study which addresses an important gap in the literature. The literature review has been conducted to a high standard, including the justification for the grey literature search. Some of the information from the grey literature search, which is currently in a supplemental file, could usefully be included in the main paper, as it is helpful and has been set out in a clear structure.</p> <p>Qualitative methodology is clearly explained and thorough.</p> <p>The findings are depressingly resonant of this reviewer's experience of the challenges in the field, and identify more barriers than solutions, although some clear themes emerge for how this complex area of commissioning should move forward. It would be worth a comment from the authors on the seemingly difficult conundrum of the need for commissioning to take account of personalisation, whilst at the same time securing pathways of care. In their reflections / discussion it would also be worth the authors making a brief mention of the wider contextual financial and professional challenges. For example, although the need for more and earlier primary care involvement - which certainly reflects a failure of paediatricians to involve GPs proactively and effectively - these is also the problem of shortfalls in the GP workforce, and limited training on transition and children and young people with complex disability.</p> <p>The diagrammatic representation of the thematic analysis, which is also currently in a supplemental file, is helpful and should be included in the main paper.</p>
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<b>REVIEWER</b>	Searle, Aidan Bristol Biomedical Research Centre (Nutrition theme), University of Bristol, UK
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	Competing interests: I declare that there are no competing interests
<b>REVIEW RETURNED</b>	12-Jun-2017

<b>GENERAL COMMENTS</b>	<p>This manuscript reports a qualitative exploration of clinical commissioners views of transition from child to adult health services in the UK. The study is well executed and the analysis is rigorous which gives the reader confidence in the reported findings. The manuscript is clearly written and includes well considered discussion of the findings and the future implications for commissioning bodies.</p> <p>However, there are a few minor issues that will improve the quality of the manuscript before it is accepted for publication.</p> <p>Methods: With regard to sampling it would be good to know reasons for non-participation and what were the roles of the non-participants to help the reader appreciate the representativeness of the participants.</p> <p>Was the interview scheduled piloted or reviewed following initial interviews? How well did the guide translate with regard to the different participant roles?</p> <p>It would be useful for the reader to have a description of Framework analysis and why it was deemed suitable to use in this context?</p> <p>Analysis: Was data saturation achieved within the subgroups of participants interviewed, please comment in Discussion?</p> <p>Discussion: Were there any noticeable differences in the quality and quantity of face to face interviews compared with telephone interviews and between participant role, i.e. candour, duration of interview etc</p> <p>I wondered if there was any data relating to transition to centralised services and potential regional disparity in service provision?</p>
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<b>REVIEWER</b>	Rajmil, Luis IMIM Hospital del Mar Institut d'Investigacions Mèdiques, Barcelona, Spain Competing interests: No competing interest to declare
<b>REVIEW RETURNED</b>	19-Jun-2017

<b>GENERAL COMMENTS</b>	<p>The study approaches an important question in healthcare services that is the transition from paediatric to adult healthcare services in children with long term chronic conditions.</p> <p>The qualitative approach seems to be adequate to analyse this subject. Nevertheless, the manuscript needs some revision to be understandable and to improve its presentation:</p> <p>1) Although the concept of transition and its potential problems and solutions are easy to understand, authors seem to present a specific process of the UK. Commissioning isn't clearly explained and who, when, and how it is performed. It is necessary to expand the introduction and clarify those aspects that seem to be specific of the UK. The manuscript would be probably very useful in other settings but it should be contextualised firstly. For example, in Spain there</p>
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	<p>are neither specific functions nor persons or organisations responsible for the transition outside the Primary and Specialty Care professionals. And it is probably more complicated than in the UK given that in most of Primary Care centres children 0-14y are controlled by paediatricians, not GP. Frequently happen that children with some specific chronic conditions such as diabetes type 1 remain with paediatric specialist services until older ages than 14y old.</p> <p>2) A more clear and in depth definition of the type of study and its methodological approach is necessary. "Interview study" is not so good definition of a qualitative type of study. It could be better to say that it is a "XXXX study (the type of study designed by the authors)" using conversational techniques for data collection.</p> <p>3) Why authors didn't include a sample of patients, who can also be an important source of information about their own experiences? Authors at least should add this fact as a great limitation of the study.</p> <p>Minor concerns</p> <p>4) In the introduction section, 2nd sentence, first paragraph: "Many of them have negative experiences...." Are there any references to cite?</p> <p>5) It is not so clear why the description of literature review is so exhaustive given that the study is not a meta-analysis</p>
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### VERSION 1 – AUTHOR RESPONSE

#### REVIEWER 1

This is a very well conducted study which addresses an important gap in the literature. The literature review has been conducted to a high standard, including the justification for the grey literature search. Some of the information from the grey literature search, which is currently in a supplemental file, could usefully be included in the main paper, as it is helpful and has been set out in a clear structure.

Qualitative methodology is clearly explained and thorough.

- Thank you for this positive feedback. We placed the information from the grey literature in a supplemental file rather than the main paper to keep the paper succinct and within the word count.

The findings are depressingly resonant of this reviewer's experience of the challenges in the field, and identify more barriers than solutions, although some clear themes emerge for how this complex area of commissioning should move forward. It would be worth a comment from the authors on the seemingly difficult conundrum of the need for commissioning to take account of personalisation, whilst at the same time securing pathways of care.

- We have added a paragraph in the Discussion second paragraph on this issue of personalisation. (page 15 )  
 "Commissioners identified clearly the inevitable tension between the need to commission for personalisation of healthcare, whilst at the same time securing pathways of care. There is no easy solution to this but probably the responsibility for personalisation should lie mainly with the provider of services, whilst the commissioner sets the required pathways of care by purchasing the necessary staff and facilities."

In their reflections / discussion it would also be worth the authors making a brief mention of the wider contextual financial and professional challenges. For example, although the need for more and earlier primary care involvement which certainly reflects a failure of paediatricians to involve GPs proactively and effectively - these is also the problem of shortfalls in the GP workforce, and limited training on transition and children and young people with complex disability.

- We agree with the reviewer's point, and have carefully considered including this. However, as the other reviews requested for the paper to be less UK-focused, we have after much debate decided not to add these (large UK-based) nuances in the discussion.

The diagrammatic representation of the thematic analysis, which is also currently in a supplemental file, is helpful and should be included in the main paper.

- Thank you, we are pleased to find that this has been helpful, we have now added this diagram just prior to the Discussion on Page 15.

## REVIEWER 2

This manuscript reports a qualitative exploration of clinical commissioners views of transition from child to adult health services in the UK. The study is well executed and the analysis is rigorous which gives the reader confidence in the reported findings. The manuscript is clearly written and includes well considered discussion of the findings and the future implications for commissioning bodies.

- Thank you!

With regard to sampling it would be good to know reasons for non-participation and what were the roles of the non-participants to help the reader appreciate the representativeness of the participants.

- Reasons for non-participation were: no response to email or email follow up; change in role; or lack of capacity to participate. Our use of a sampling framework ensured representation from each set of participant sub groups. We have added a paragraph on this at the start of the Results section on Page 7.

Was the interview schedule piloted or reviewed following initial interviews? How well did the guide translate with regard to the different participant roles?

- We have added the following paragraph to the Methods section under data collection Page 5. The interview schedule was piloted with ALC who had both clinical and academic experience of transition and commissioning. The interview guide was designed to use open questions, which were used dynamically (as described in Table 2). Questions were not adapted for different roles, rather the use of probes was tailored to fully elicit different experiences between roles.

It would be useful for the reader to have a description of Framework analysis and why it was deemed suitable to use in this context?

- The paragraph below describing framework analysis and why it is suited our study is included in Methods under data analysis on Page 5.  
"Framework analysis allows both emergent data themes and the explicit recognition and use of a priori issues in the analytical framework. Framework analysis is increasingly being used within

health services research, and it fitted the aims of our study as we had pre-defined areas we wished to investigate while remaining open to the emergence of further topics and themes. A series of interconnected steps within the framework approach describe the processes that guide the systematic analysis, these steps allows an iterative refinement of themes and are described below”

Was data saturation achieved within the subgroups of participants interviewed, please comment in discussion?

- Yes, data saturation was reached and a sentence to acknowledge this has been included in the third paragraph of Discussion, Page 16.

Were there any noticeable differences in the quality and quantity of face to face interviews compared with telephone interviews and between participant role, i.e. candour, duration of interview etc.

- There were no patterns in length or quantity of interviews between participant roles. All but three of the interviews were conducted face to face and we have added a sentence to this effect in the Methods, data Collection, Page 4.  
'Interviews had a median length of 45 minutes, with range between 27-68 minutes.'

I wondered if there was any data relating to transition to centralised services and potential regional disparity in service provision?

- This did not emerge as a finding or a theme.

### Reviewer 3

The study approaches an important question in healthcare services that is the transition from paediatric to adult healthcare services in children with long term chronic conditions.

- Thank you, we agree.

The qualitative approach seems to be adequate to analyse this subject. Nevertheless, the manuscript needs some revision to be understandable and to improve its presentation:

- Thank you for these helpful further enhancements.

1) Although the concept of transition and its potential problems and solutions are easy to understand, authors seem to present a specific process of the UK.

Commissioning isn't clearly explained and who, when, and how it is performed. It is necessary to expand the introduction and clarify those aspects that seem to be specific of the UK.

- A description of commissioning and then text about the UK context has been added to the Introduction second paragraph on Page 3:  
“In the UK over the last 20 years there has been a fundamental separation of the bodies that commission services from the bodies that provide them. Some specialised services are commissioned centrally and more general services are commissioned by local groups with strong representation from primary care.”

The manuscript would be probably very useful in other settings but it should be contextualised firstly. For example, in Spain there are neither specific functions nor persons or organisations responsible for the transition outside the Primary and Specialty Care professionals. And it is probably more complicated than in the UK given that in most of Primary Care centres children 0-14y are controlled by paediatricians, not GP. Frequently happen that children with some specific chronic conditions such as diabetes type 1 remain with paediatric specialist services until older ages than 14y old.

- The reviewer's description of Spain seems to converge with the findings we present – i.e. the complexities of multiple organisations having a role as opposed to specific persons/organisations, paediatricians leading child health rather than GPs, etc.

As requested, to further contextualise and to reflect that there may be general lessons from our study, we have added a paragraph in the Discussion, on Page 16:

"It is difficult to compare commissioning/purchasing regimes across different countries. It is inevitable that services will differ across countries, just as they do across regions in the UK, but this is not the reason it is difficult to compare commissioning arrangements. Rather the underlying financing leads to very different arrangements. For example the system in the US is largely set by insurance companies that itemise every aspect of care so that it can be billed."

2) A more clear and in depth definition of the type of study and its methodological approach is necessary. "Interview study" is not so good definition of a qualitative type of study. It could be better to say that it is a "XXXX study (the type of study designed by the authors)" using conversational techniques for data collection.

- Within qualitative research 'interview study' is a recognised, established methodology and we note that the two other reviewers considered the study methods generally well described. As requested, we have expanded the text to note that the study used conversational techniques to gather data at the start of Methods, Page 4.

3) Why authors didn't include a sample of patients, who can also be an important source of information about their own experiences? Authors at least should add this fact as a great limitation of the study.

- Including patients was beyond the scope of the present study. As in all studies, decisions had to be made about key participants, and as this was the first study on commissioning for (rather than on patient experience of) transition we prioritised people involved in and with experience of commissioning. We have added the following text to the Discussion in the strengths and limitations section to make this explicit, on Page 16.  
"We did not approach young people to ask their views about commissioning because in the UK commissioning is a separate from service provision and patients for the most part only experience services. Young people in transition have the major task of gradually taking responsibility for their own healthcare in the context of the services available; we thought it unlikely they would have knowledge of commissioning. Efforts have been made to engage the public in the work of commissioners but this has been very difficult and especially difficult to engage adolescents in discussions about commissioning (new reference 17 now cited).

4) In the introduction section, 2nd sentence, first paragraph: "Many of them have negative experiences...." Are there any references to cite?

- The five references we already cited at the end of these two sentences support both the points about negative experiences and fragmented outcomes.

5) It is not so clear why the description of literature review is so exhaustive given that the study is not a meta-analysis

- Given the lack of literature on the topic, we wanted to be clear about the extensive processes undertaken to gather literature. We also wanted to include this to enable others to make use of the review, and thus avoid future duplication of effort. The detail is included in a supplemental file rather than the main manuscript.