PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis
AUTHORS	Davison, Gail; Kelly, Martina; Conn, Richard; Thompson, Andrew; Dornan, T

VERSION 1 – REVIEW

REVIEWER	Soto Beauregard, María del Carmen Complutense University of Madrid, Salud Pública y Materno-Infantil
REVIEW RETURNED	21-Feb-2021

GENERAL COMMENTS	I appreciate the opportunity to review this interesting work on the relationship of healthcare professionals with pediatric patients and its influence on the "improved health outcome" within the important framework of patient-centered care. Its meta-analysis nature does not allow the differentiation of subgroups by type of pathologies (acute, chronic or palliative care), type of health institution (public / concerted / private) and demographic, social and cultural characteristics of the children and adolescents assessed. The limitations collected by the authors reinforce the need to propose a multi-institutional prospective study where guidelines can be obtained for assessing the needs for interrelation and communication between health professionals and pediatric patients with the aim of establishing a general action guide that allows for the increment of the quality of care provided to children and adolescents.

REVIEWER	Nicholson, Emma University College Dublin
REVIEW RETURNED	01-Mar-2021

GENERAL COMMENTS	This scoping review and interpretive synthesis outlines findings from an important area of study. The protocol for the review was very thorough; however, I have serious concerns regarding some elements of the methodology and results that need to be addressed before this paper would be suitable for publication. I am recommending that the paper be rejected in it's current form but I would encourage the authors to re-submit once they have revised the review. Introduction Page 7, line 135: can you provide more context on what you mean by 'co-producing'. Do you mean including children's voices in a co-design process for health services?

	Method Can the authors provide more information about interpretive synthesis? What does it entail and what does it add to the review? A sentence or two would suffice. Page 9, line 171: Was there any particular framework that informed the selection of the search terms (e.g., PICO, PST etc.)? I think the search terms should be included in a table in the main document as they are important for the reader to see as they read the review. Page 9, Line 170: I have concerns about definition of a 'child' used in the review. The inclusion criteria state they were up to the age of 18 but from table 2 it seems that they also included those aged 18. Can the authors clarify this? What was the rationale for including all patients aged 18 and under? Did each individual study define a paediatric patient in the same way? It can vary across jurisdictions, but an 18-year-old would typically be deemed an adult and treated in adult services. I am aware that they are sometimes treated in paediatric services (particularly if they are transitioning from paediatric to adult health services) but grouping all those aged 18 and under together is problematic for the overall findings of the study as they would have different needs and experiences compared to other age groups. At the very least, I would recommend the authors revise the review to exclude those aged 18 from the analysis. Box 2: Was methodology considered an inclusion/exclusion criteria? 'Qualitative Research' was a search term so it appears that only qualitative research was included and that should be clearly stated in the paper. Page 10, line 188: Did the second reviewers double screen 100% of records? How exactly were disagreements dealt with? Page 12. Please state clearly that thematic analysis was the analytic technique applied. Can the authors provide some further detail about the actual process that was undertaken (i.e., line-by-line coding, generating themes etc.)? Page 12, line 227: From where was ethics approval obtained? Can you provide a reference number for ethical approval? Page 13, line 234: Please ensure the use of past tense throughout. Did the authors assess methodological quality of the papers that were included in the review? I am aware that it is not always necessary for scoping reviews but Levac et al (2010) certainly discussed the need for a minimal level of quality assessment as a means to legitimize findings from scoping reviews. Given the authors are making recommendations and not merely mapping existing literature, I think it would be warranted for this review. Results I would question the value of the additional scoping review results and the multiple figures and data presented at the end of the paper. From what I can see, they generally repeat what is already

	in the main text and in Table 2 and it's quite burdensome for the reader to wade through. Page 20, line258-260: Please provide the exact % of quotes that were accompanied by age and gender data. From my calculations it is about 59% so I would provide a figure rather than 'most'. I'm a little concerned about the initial coding process which defined experiences as positive and negative as it seems a bit simplistic for a thematic analysis. Can the authors provide more information about how they went from coding data as positive and negative to 'forming trusting relationships" and "involvement in healthcare discussions and decisions'? On page 12, the authors state they used Braun and Clarke but it's not clear how many initial themes emerged and how they were then revised to the final themes. Page 24, Stakeholder Consultations: I think this is a nice addition to the review, however, was there a topic guide for the discussions in the focus group? If so, could the authors include it? Page 28, line 406-407: Can you clarify the nature of these limitations? The data table provides detailed breakdown of sub-specialties (e.g., mental health) so it's difficult to see how it would not be possible to do sub-groups analyses using these groupings (at least for some of the sub-groups). It seems that different groups would have different experiences and needs (e.g., ASD patients). This is also relevant to age groups as a 5-year-old would have very different communication needs and experiences compared to 16–18-year-olds who would be deemed adults in many services. Discussion Page 26, Line 369-370: The first sentence is confusing so I would recommend re-wording. Page 27, line 382-384: I'm not sure the authors can infer from the review findings that ages and clinical contexts can influence involvement preference when no sub-group analyses were conducted. I would recommend removing that sentence. The discussion section needs to draw much more from the existing literature and highlight what this review adds to the literature in this area. It would also be beneficial to discuss highlight areas of research for this area. Page 28, line 421: I would be hesitant to state that the paper provides a concrete framework and would suggest removing this phrase.

VERSION 1 – AUTHOR RESPONSE

Response to reviewers' and editor's comments

bmjopen-2021-049683 entitled "How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis"

	No.		Reviewers’ and editor’s comments	Authors’ comments	Amendments, where relevant
Positive comments	1	R1	I appreciate the opportunity to review this interesting work on the relationship of healthcare professionals with pediatric patients and its influence on the "improved health outcome" within the important framework of patient-centered care.	We note that R1 found the work interesting, R2 regarded it as an “important area of study”, and R2 regarded the protocol as thorough. These comments attest to the potential value of the article.	N/A
	2	R2	This scoping review and interpretive synthesis outlines findings from an important area of study.		
	3	R2	The protocol for the review was very thorough.		
Major concerns: **Metho-dology**	4	R2	However, I have serious concerns regarding some elements of the methodology and results that need to be addressed before this paper would be suitable for publication.	Both reviewers apply positivist assumptions to a review, whose validity does not rely on those assumptions. R1, for example, applies the quantitative term ‘meta-analysis’ to our qualitative evidence synthesis. R2 demonstrates unfamiliarity with the term ‘interpretivist’, which we had assumed was in such general use that it did not need explanation. R2’s ‘serious concerns’ result, we suggest, from a misapprehension. The Sage Handbook of Qualitative Research,(1) which we have now cited, argues that both ‘hard’ and ‘soft’ data can be valid but for different purposes. ‘Hard data’, it states, are descriptive data (eg the numerical information R2 requests). Soft data, in contrast, are experiential data. The Handbook author regards ‘soft data’ as more informative for research into human experience, and	Both reviewers’ critiques pointed out the need to explain the rigour of our work more clearly to people who are unfamiliar with or unsympathetic to constructivist research methodologies. We have included a methodological orientation at the start of the METHODS section (lines 143-156), using what we hope is language that non-qualitative researchers will find helpful, to explain the nature, and relevance of our methodology. We have included more information about how we maintained reflexivity, which underpins qualitative rigour, later in the METHODS section (lines 181-183 and 215-236). If the editor or reviewers would like us to include further explanations, we will be happy to provide these.
	5	R2	I am recommending that the paper be rejected in it’s current form but I would encourage the authors to re-submit once they have revised the review.		
	13	R1	Its meta-analysis nature does not allow the differentiation of subgroups by type of pathologies (acute, chronic or palliative care), type of health institution (public / concerted / private) and demographic, social and cultural characteristics of the children and adolescents assessed.		
	14	R2	Can the authors provide more information about interpretive synthesis? What does it entail and what does it add to the review? A sentence or two would suffice.		

				sometimes able to contradict quantitative data. Our article makes very clear that it seeks to explore the experiences of CADs. We are also clear that we want our research to centre on the child or adolescent, rather than be directed by the a priori assumptions that have to be made to ensure that data are 'hard'. In technical terms, this research has a constructivist epistemological orientation. Both reviewers have questioned the validity of the research by holding it up to the inapplicable standards of 'hard' data gathering. We hope that this explanation will relieve the editor of concerns raised by the reviewers about the rigour of the work. It is rigorous, but not in the way the reviewers assumed was the only possible way.	
Major concerns: **Age range**	17	R2	Page 9, Line 170: I have concerns about definition of a 'child' used in the review. The inclusion criteria state they were up to the age of 18 but from table 2 it seems that they also included those aged 18. Can the authors clarify this? What was the rationale for including all patients aged 18 and under?	This review concerns children and adolescents. The age range used, 0-18 years (inclusive), is consistent with UNICEF's authoritative definition of children, and adolescents, (where adolescents are defined as persons between the ages of 10 and 19 years).(2) Whilst variations exist, we judged the inclusion of	We agree that more detail is required on the age limit. We have included additional detail (and references) in the: 1. Abstract: line 42. 2. Methods, line 175 3. Methods, table 1 (limits) 4. Methods, box 1 (point 1 & 4) 5. Methods, table 2A (inclusion 3 & exclusion 1)
	18	R2	Did each individual study define a paediatric patient in the same way?		
	19	R2	It can vary across jurisdictions, but an 18-year-old would typically be deemed an adult and treated in		

			adult services. I am aware that they are sometimes treated in paediatric services (particularly if they are transitioning from paediatric to adult health services) but grouping all those aged 18 and under together is problematic for the overall findings of the study as they would have different needs and experiences compared to other age groups. At the very least, I would recommend the authors revise the review to exclude those aged 18 from the analysis.	18-year-old adolescents as appropriate, because, in addition to UNICEF's definition, it is consistent with an international trend towards increasing paediatric age ranges to incorporate late adolescents.(3,4) Our approach aligns with published research, which commonly includes adolescents aged 18 years, as shown in table 3. A smaller group of studies, which we <u>excluded</u>, included 'adolescents' up to 22 years.(5–8) No papers used the term 'paediatric patient'. In addition to the above, it would be technically impossible to exclude adolescents aged 18 to 19 years, without also excluding adolescents as young as 12. This is because studies quote age ranges in years (rather than years and months) and do not always provide additional demographics or ages with quotations.(9–11)	6. Methods, table 2B (inclusion 3 & exclusion 1) 7. Methods, lines 196-198 8. Methods, lines 203-205. 9. Included references 44,45, & 46
Abstract	6	Editor	Please revise the formatting of your abstract so that it includes the following sections: Objectives >> Design >> Data Sources >> Eligibility Criteria >> Data extraction and synthesis >> Results >> Conclusions.	We appreciate this advice about formatting.	The revised abstract is formatted as you have requested.
Introduction	7	Editor	Please remove the quote from the beginning of the introduction section.		We have removed the quote.
	8	R2	Page 7, line 135: can you provide more context on what you mean by 'co-producing'. Do you mean including children's voices in a co-design process for health services?	The term 'co-producing' or co-production refers to a way of working, where providers and services users work in <u>equal</u>	We have changed the term to co-production (as it is more commonly known) and elaborated the use of the term on

				partnership to effect change.	lines 121-122, to make this clearer. We have included an additional reference (24).
Methods	9	Editor	Please also work on improving the reporting of the methods e.g. which databases were searched? What were the dates of coverage?		We have extensively revised the methods section to respond to your request and the reviewers'. In particular, we have: 1. Added a methodological orientation section, lines 141-156 2. Elaborated on steps 2,3, and 5 (in methods), lines 172-177, 214-246, and table 1 (types of studies).
	10	Editor	The literature search is more than 12 months old now. Can this be updated?	We appreciate the editor asking if it is feasible, rather than making this a condition of acceptance. The process of searching and selecting the type of qualitative data we included involves a huge task of sifting and sorting, which has already yielded a 'sufficient' dataset, which is the qualitative arbiter of rigour. Braun & Clarke's checklist advises taking sufficient to analyse qualitative data. If we re-ran the searches, the revision would likely take more than 12-months and therefore still be 'out of date' at the time of publication. This qualitative synthesis, though, examines enduring human qualities and behaviours which are far less time-sensitive than, for example, a RCT. We recognise this as an inherent limitation	We have included a comment about this as a limitation and noted the non-time-sensitive nature of the data: - Discussion, lines 408-412.

				but do not regard it as a serious validity threat.	
	11	Editor	Please remove the published protocol article from the supplementary files. This should just be cited at the beginning of the methods.		We have done this and updated line 158.
	12	Editor	If you need to deviate from the pre-specified protocol as a result of the concerns raised by the reviewers above, then please add a sub-section to the methods section explaining what deviations have taken place and why these changes were necessary.	We agree that the reviewers' comments could lead us to deviate from the protocol but, for reasons explained in our comments about methodology, above, deviating from our protocol would be incompatible with our original methodological choice and therefore worsen rather than improve the article.	Please see our responses to points 4, 5, and 13 above, which we believe strengthen the article by more fully explaining why the suggestion of the reviewers to change the nature of the research is not warranted.
	15	R2	Page 9, line 171: Was there any particular framework that informed the selection of the search terms (e.g., PICO, PST etc.)?	We used the PCC (population, context, and concept) framework, recommended in the Joanna Briggs Institute Reviewers' manual.	We have updated line step 2 in methods, lines 172-175 and added reference 43.
	16	R2	I think the search terms should be included in a table in the main document as they are important for the reader to see as they read the review.	We agree that the search terms should be accessible to the reader, however, including further tables in the main document may reduce readability.	The Ovid MEDLINE search can be accessed in supplementary file 2 and is clearly cited on line 172 and table 1. We would be willing to move the table into the main document, if the Editor prefers.
	20	R2	Box 2: Was methodology considered an inclusion/exclusion criteria? 'Qualitative Research' was a search term so it appears that only qualitative research was included and that should be clearly stated in the paper.	Methodology, specifically, was not an in/exclusion criterion; any study quoting CADs verbatim was evaluated against the defined criteria. The fact that an article quoted CADs verbatim showed that, for our purposes, the methodology of the primary research was informative.	We have provided additional clarity in methods (table 1 (types of studies and line 175).

	21	R2	Page 10, line 188: Did the second reviewers double screen 100% of records? How exactly were disagreements dealt with?	Second reviewers screened 10% of articles and supported the 1st reviewer in the selection process, by discussing results, study contents, and eligibility. We adopted an iterative approach as described by Levac et al. When 1st or 2nd reviewers were unsure, we discussed the studies, clearly articulating how the evidence related to the research question and wider methodological constructs. The criteria were updated accordingly, and, as a final validity check, the 1st reviewer reviewed all records and annotations against the definite criteria. All authors reviewed the included articles and all extracted quotations.	We have added further details in: - Methods, step 3, lines 178-194, and table 3A&B
			Page 12. Please state clearly that thematic analysis was the analytic technique applied. Can the authors provide some further detail about the actual process that was undertaken (i.e., line-by-line coding, generating themes etc.)?	Thematic analysis was not the sole analytic technique; the review went beyond simple theming of findings to conducting an interpretive synthesis.	We have revised the manuscript substantially to explain to readers why the findings go beyond a simple thematic analysis, as referred to by R2. Specific places where we have done this are: 1. Abstract, lines 34-37 and 46-48. 2. Intro, lines 132-140. 3. Methods, lines 143-156 and 215-227.
	22	R2	Page 12, line 227: From where was ethics approval obtained? Can you provide a reference number for ethical approval?	The details can be found in the 'Ethics approval and consent to participate' section, in declarations (lines 445-448).	N/A
	23	R2	Page 13, line 234: Please ensure the use of past tense throughout.		We have amended this (lines 258-260).

		R2	Did the authors assess methodological quality of the papers that were included in the review? I am aware that it is not always necessary for scoping reviews but Levac et al (2010) certainly discussed the need for a minimal level of quality assessment as a means to legitimize findings from scoping reviews. Given the authors are making recommendations and not merely mapping existing literature, I think it would be warranted for this review.	Our response to point 20, above, covers this comment. Since the articles we reviewed gave us access to verbatim quotes, but we did not include authors' analyses of those quotes, we do not see the relevance of assessing methodological quality.	We have added further clarity and an explanation to methods (lines 199-203).
Results	24	R2	I would question the value of the additional scoping review results and the multiple figures and data presented at the end of the paper. From what I can see, they generally repeat what is already in the main text and in Table 2 and it's quite burdensome for the reader to wade through.	The figures and additional data presented after the paper are supplementary information, meaning that the reader does not need to wade through it; rather, it is optional. The published protocol clearly outlines (on page 4) how descriptive data will be analysed and presented. Removing the data from supplementary files would prevent readers (who are interested) from accessing the information, leave gaps in the results, and contradict the guidance on data accessibility from open access journals.	We have not omitted any supplementary files, however, we would be willing to under Editorial guidance.
	25	R2	Page 20, line258-260: Please provide the exact % of quotes that were accompanied by age and gender data. From my calculations it is about 59% so I would provide a figure rather than 'most'.	We agree that 'most' is inappropriate, however, quantitative judgements do not sit comfortably in qualitative research. We would not want to distract from the rich qualitative findings by giving percentages.	We have changed the wording to 'many' rather than 'most' and would be willing to change it to 'some' if the Editor would prefer. We have included the exact percentage in the supplementary file 5.
	26	R2	I'm a little concerned about the initial coding process which defined experiences as positive and negative as it seems a bit simplistic for a thematic analysis. Can the authors provide more information about how they went from coding	R2 raises two concerns. One is a concern about the apparently simplistic dichotomisation of emotions. The other as about the procedural steps that led to the final	We have included further detail in Methods, lines 231-243. 1. We have added an explanation of the

			data as positive and negative to 'forming trusting relationships" and "involvement in healthcare discussions and decisions'?	interpretation. We address these in turn: 1. Psychologists use the metaphor of 'valence' to refer to the positivity or negativity of emotions, which is why we used those terms. We appreciate that some readers might, like R2, need this explained and might baulk at the polarity. We do not, though, acknowledge this as a methodological weakness. 2. Point 14, above, shows that positivistically-inclined readers need the concept of interpretation to be explained more clearly. We acknowledge this as a need for explanation, but not as a methodological weakness.	concept of valence (lines 233-235) and, to protect other readers from feeling the same discomfort as R2, changed the words we use to describe polarity to 'favourable' and 'unfavourable'. 2. Our revision has quite extensively addressed readers' potential unfamiliarity with interpretive research; for example, in lines: 35-37, 47-48, 71-74, 135-140, 146-15, 228-231, and 401-405.
	27	R2	On page 12, the authors state they used Braun and Clarke but it's not clear how many initial themes emerged and how they were then revised to the final themes.	Again, the reviewer is asking for quantitative information in this qualitative research. Qualitative validity resides not in numbers but in researchers' reflexive engagement with the data and readers' reflexive responses to the findings.	We have strengthened our explanation of the thematic analysis in lines 215-227. We would be happy to provide additional details on candidate themes and how they led to the final thematic structure in a supplementary file, if required.
	28	R2	Page 24, Stakeholder Consultations: I think this is a nice addition to the review, however, was there a topic guide for the discussions in the focus group? If so, could the authors include it?	We did not use a topic guide; we presented the candidate themes with exemplar quotations and asked participants to discuss.	We have re-worded lines 251-253, to make this clearer.
	29	R2	Page 28, line 406-407: Can you clarify the nature of these limitations? The data table provides detailed breakdown of sub-	Subgroup analysis was not possible, despite R2's opinion to the contrary, because the	We have added further detail on the

			specialties (e.g., mental health) so it's difficult to see how it would not be possible to do sub-groups analyses using these groupings (at least for some of the sub-groups). It seems that different groups would have different experiences and needs (e.g., ASD patients). This is also relevant to age groups as a 5-year-old would have very different communication needs and experiences compared to 16–18-year-olds who would be deemed adults in many services.	metadata provided by original authors was not precise or detailed enough to make this possible, as shown in table 2 (contextual information).	incompleteness of meta-data: - Limitations sections, lines 418-421.
Discussion	30	R2	Page 26, Line 369-370: The first sentence is confusing so I would recommend re-wording.		Grammatical error amended (line 379).
	31	R2	Page 27, line 382-384: I'm not sure the authors can infer from the review findings that ages and clinical contexts can influence involvement preference when no sub-group analyses were conducted. I would recommend removing that sentence.		We agree with this statement and have removed the sentence.
	32	R2	The discussion section needs to draw much more from the existing literature and highlight what this review adds to the literature in this area. It would also be beneficial to discuss highlight areas of research for this area.	We are puzzled that, having given a detailed synthesis of the entire literature, the reviewer sees a lack of literature citations as a shortcoming. We have reported, in the discussion section, the only comparable syntheses known. There is nothing to add, at least as far as the literature is concerned.	We suggest that the main purpose of the discussion section of a secondary research article is to discuss limitations to the transferability of the findings and, with that in mind, the implications to practice and research, which the article presents.
	33	R2	Page 28, line 421: I would be hesitant to state that the paper provides a concrete framework and would suggest removing this phrase.		We have removed the word 'concrete' from line 398.
	34	R1	The limitations collected by the authors reinforce the need to propose a multi-institutional prospective study where guidelines can be obtained for assessing the needs for interrelation and communication between health professionals and pediatric patients with the aim of establishing a general action guide that allows for the increment of the quality of care provided to children and adolescents.	We note the reviewer's comment but feel it is rather remote from the intent of this work.	N/A

References:

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